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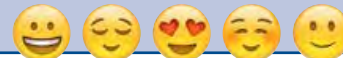


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Technology has made it possible for friends and family to see all of the wonderful things that are happening at ARC of Rockland in real time.

For that reason, we will no longer publish Highlights & Happenings in ARCLIGHT Magazine. Instead, we urge you to like us on our various Facebook pages: ARC of Rockland, Prime Time Schools of Rockland, A Taste of Rockland, Strawtown Jewelry, Glaze Pottery and Art Studio and ARC HealthResources. Please visit our websites at www.arcofrockland.org, www.primetimeschools.org and www.strawtownjewelry.com. Whether you are at work, at home, or out jogging. Whether you find us on your phone, your ipad or your laptop—wherever you are—we’re right there with you.



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From the President

Dian Cifuni

With this, my first column as President of ARC of Rockland, I take the opportunity to speak to the adult siblings of people with intellectual and other developmental disabilities.

We brothers and sisters have an obligation to show our gratitude to the agency that cares for our family members in so many ways. It is a fact that in most instances, it is parents who attend agency fundraisers, volunteer their time and donate money. But, from my point of view, we too have a responsibility to our siblings—and therefore, we have a responsibility to ARC.

Right now, when government funding for services has been cut to a minimum, it is essential that we contribute to this outstanding organization. Yes, the basics will likely always be here for our brothers and sisters. But

the vital extras—recreation programs, respite services, employment services—these offerings require our financial support.

How we give, how much we give and when we give are matters of personal choice. But I believe that we should give. As a start, I recommend that every adult brother and sister of a person with a developmental disability become an ARC Family Friend. For an extremely reasonable annual fee paid over a 12 month period, you will demonstrate your commitment to ARC and in return, you will receive tickets to *A Taste of Rockland*, luncheon at the annual *Golf Classic* and the recognition due those who choose to stand up for an agency that stands by the people we love.



From the Chief Executive Officer

Carmine G. Marchionda

This issue of *ARCLIGHT Magazine* places Down syndrome front and center.

There is no question that people with Down syndrome are increasingly involved in the

mainstream of society. Children attend schools along with peers who do not have developmental disabilities. Adults engage in satisfying volunteer and career activities. People of all ages are involved in every aspect of community life. An understanding of Down syndrome and attitudes towards people with Down syndrome have markedly improved in recent years.

In the following pages, medical professionals, parents and people with Down syndrome tell stories of courage, optimism and success. You will meet Kody Conover, the award-winning golfer with Down syndrome and Katie Foreman, a young woman with Down syndrome who has found her ideal career.

In the realm of research, Dr. Jamie Edgin sheds light

on sleep apnea, known to affect learning in children with Down syndrome. Dr. William C. Mobley describes studies in Alzheimer's disease that offer hope for participants with Down syndrome and ultimately for the general public. Dr. Brian Skotko describes the benefits of being the sibling of a person with Down syndrome. Taken together, these articles and others provide an overview of the topic.

From its inception, ARC of Rockland has been a provider of services, an advocacy organization and a resource for people with developmental disabilities. *ARCLIGHT Magazine*, published twice yearly by ARC of Rockland is, primarily, a vehicle for education. We believe that this purpose is best served by focusing on a single area of interest with each issue of the magazine. Experience has taught us that innovations and insights in one field of study often have broader implications. We hope that you agree.

Introducing Dian Cifuni

*President,
ARC of Rockland*

Dian Cifuni accepted the role of president of ARC of Rockland at a May 18th swearing in ceremony at ARC of Rockland headquarters in Congers, NY. "I believe in the importance of ARC and all that it stands for," she says. "But more importantly, I believe that as the sibling of a person with a disability, it is my responsibility to give back to the agency that has given so much to us."

Ms. Cifuni has been a member of the ARC Board of Directors since 1988. She comes to the position of president with a wealth of experience in the not-for-profit world. She has served as Director of Finance for United Way of Rockland since 2008. She is the volunteer Director of Finance for Together Our Unity Can Heal (TOUCH), a nutrition and non-Medicaid case management program for people with chronic illnesses. She is also the volunteer Events Coordinator of the Welfare League, a NYSARC Chapter dedicated to recreational and social activities for people with intellectual and other developmental disabilities in Rockland County. Her responsibilities with that organization include overseeing and organizing theme dances, an annual picnic and a yearly vacation trip for participants.



Dian with her sister Carol

The new president of ARC of Rockland holds a Bachelor's Degree of Business Administration in Accounting, an Associate's Degree in Applied Science and credits towards a Master's Degree in Management Science focusing on hospitality management, travel and tourism.

One of seven siblings, Ms. Cifuni's immediate family and a host of aunts, uncles and cousins lived within close proximity of one another. "We grew up in what was originally a bungalow colony on a lake in Congers, New York," she says. "My sister Carol was always around family. She saw at least 20 relatives every day, and she knew everybody in town."

When their mother Veronica Cifuni died in 2004, Carol spent time between the home of her brother James of Haverstraw, NY, and Dian's home in Garnerville, NY. "After two years, Carol moved in with me full time," says Ms. Cifuni. "I have heard parents say that after they are gone, they don't want their child with a disability to be a burden on their other children. I would never say that my sister is a burden. My parents taught me that family comes first, and Carol is family."

The Cifuni sisters have worked out a schedule that suits their needs. Dian sees her sister off in the morning when an ARC driver picks her up to take her to her first destination of the day. Carol has recently joined one of

the *ARC in Motion* groups designed to accommodate the mutual interests of participants. Carol's day sometimes starts at ARC's recently-purchased Glaze Pottery and Art Studio in Orangeburg, NY, after which she and other members of the group spend time volunteering or enjoying educational or recreational activities in the County and surrounding areas.

When her sister arrives home, "I give her dinner—sometimes we eat together, and then Carol's Residential Habilitation Specialist comes to the house. Most evenings, she takes her sibling out somewhere—to the mall, to shop, to get a haircut, to visit a friend. That gives me the time to see my friends."

Before her sister came to live with her, Dian Cifuni might have left a bit later for an evening out. "But now, I meet my friends at 5 and by 8 or 8:30, I am running out the door to get home in time for the Res Hab worker to leave." Occasionally, Carol joins her sister and her sister's friends. And often, the Cifuni women take day trips together. "Carol likes to go to places like the Bronx Zoo, Bear Mountain or the Crayola Experience where we can walk around. She likes to be active." Sunday morning Church services at the Marian Shrine in Stony Point are a highlight of the week. "The priest knows Carol and always gives her a warm greeting."

When she is not working, or involved in ARC business, Dian Cifuni enjoys spending time abroad. "Travel is my respite," she explains. "I always thought that travel would be a large part of my retirement. That is why I was working towards a Master's degree in the field. I imagined that I would work on a cruise ship six months each year and handle taxes privately during the other six months." Now that she shares her home with her sibling, lengthy trips are no longer an option. But several times each year, the younger Ms. Cifuni spends

a week or two in ARC's Respite home while her sister visits countries across the ocean. "I've gotten to every continent except Antarctica and I just returned from the Baltic countries," she says. "When I am away from

home, I call several times. I don't want Carol to think I have forgotten her. And I make sure that my brother Jimmy visits her and takes her for rides."

ARC of Rockland's new president is eager to shoulder the responsibilities of this

position. "ARC has been a second home to my sister. The compassion and skill with which the staff support Carol has had a positive and lasting impact on her life and on my life. I intend to work with and for the members of ARC as we move forward with the strength and determination for which ARC has always been known." ■

"My sister Carol was always around family. She saw at least 20 relatives every day, and she knew everybody in town."

—Dian Cifuni

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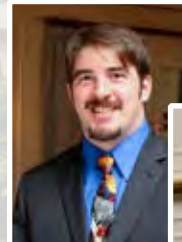
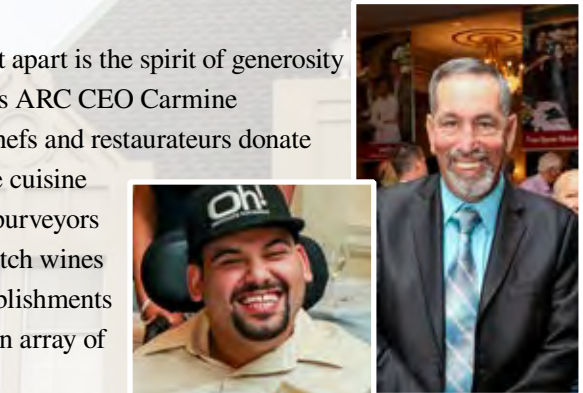
SPECIAL THANKS TO MINDWORKS FOR EVENT SPONSORSHIP

ARC of Rockland's 2016 *A Taste of Rockland* took place September 26th at the Hilton Pearl River. The red-carpet fundraiser featured delicious fare from more than 40 restaurants and purveyors of fine wines and spirits plus a sumptuous Dessert Showcase and a spectacular Silent Auction.

"What sets this annual event apart is the spirit of generosity that pervades the evening," says ARC CEO Carmine Marchionda. "Each year, the chefs and restaurateurs donate their time, talents and all of the cuisine for the evening. The beverage purveyors donate a wide variety of top notch wines and spirits and the dessert establishments go out of their way to present an array of mouth-watering confections.

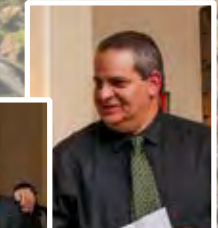
"We are grateful to the more than 350 guests whose presence at the *Taste* is essential to the success of the event, to the volunteers who serve as hosts throughout the evening and to our *Taste of Rockland* Committee, the members of which are integral to the planning and production of the affair, including the solicitation of gifts for the Silent Auction."

Kudos to participants in ARC's *ARC in Motion* initiative for delivering *A Taste of Rockland* posters to all participating restaurants. Hats off to the staffers, people who receive supports through ARC, family members and friends who painted the pitchers and bowls that served as elegant centerpieces for the *Taste*. These works of art were created at ARC of Rockland's Glaze Pottery & Art Studio in Orangeburg, NY. In another art-related project, our gratitude goes to ARC artists for the beautiful food-related paintings presented as gifts to



Continued on page 8

and a taste of the best."



"This was the best *Taste* ever..."

Continued from page 6

each of the chefs and beverage purveyors. These original works were created in ARC art classes under the direction of artist Lauren Rudolph, owner of *Little Light Art Studio*, Nyack, NY.

"We owe a special thanks to Joseph Lagana for the Lagana Challenge, now in its fourth year. The 2016 challenge garnered \$20,000 for ARC," says Harold Peterson, chairperson of the *Taste* and President of the ARC Foundation of Rockland. "Once again, we offer our heartfelt appreciation to the New City Little League for its donation of \$6,800 raised during the annual New City Little League Tournament for the benefit of ARC."

Says Mr. Peterson, "What strikes me most about *A Taste of Rockland* is the coming together of our community for one memorable evening overflowing with great food, great drinks and great hearts."



Hole in One

Golfer Takes Down Syndrome in Stride

Twenty-one year old Kody Conover is a well-known figure on the Golf Channel Am Tour. He has won more than a half dozen first place trophies in the last two years. By all accounts, he is a serious athlete with a bright future. He just happens to have Down syndrome.

The son of Kitty and Clifford Conover, Kody was diagnosed shortly after birth. “I was still in a fog when a case worker came in to tell me that he would have problems—respiratory problems, heart problems—and then, she asked if by chance I wanted to institutionalize him,” says Ms. Conover. “I was livid. I said, ‘How dare you ask me that?’”

Although they were not initially familiar with Down syndrome, the Conovers learned quickly. At three weeks, Kody began receiving Early Intervention services in California where the family was living at the time. “The physical therapist taught us so much about being parents of a child with a disability. I don’t think Kody would be doing as well as he is today if not for her. Kody’s parents enrolled him in a preschool Head Start program when he was three years old. At the age of four, the family moved to Utah where Kody continued his education. He graduated from Roosevelt Union High School in 2014 with a 3.7 GPA.

For a brief period of time, between first and second



“You must believe in yourself and have patience.” —Kody Conover

grade, Kody was homeschooled by his grandmother, the late Alice Conover. “She was phenomenal,” says Kody’s mother. “She worked with him and worked with him. We used sign language with Kody until he learned to talk at the age of four. Then, we stopped the sign language. By second grade, the Conovers enrolled Kody in East Elementary, a public school in Roosevelt, Utah. “He was one of the first children to be mainstreamed there at that age. From that point on, he was in a regular classroom and would go to a resource room for reading and math. He grew up with all of the kids here, and they grew up with him.”

When they felt it necessary, the Conovers hired a tutor for Kody during his high school years. “We paid

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Hole in One

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privately for whatever he needed,” recalls Ms. Conover. Their goal, however, was to ensure inclusion in as many aspects of education as possible. And their efforts paid off.

“When Kody stood up to speak at his high school graduation, his whole class stood up behind him and gave him a standing ovation. That’s when I broke down and cried,” says Ms. Conover. “Kody is what he is today because of these kids. I have never seen another community put their arms around somebody the way they did for Kody. We are pretty proud of Kody. But the thing is, he had these people, this support group.”

Although golf is the young Mr. Conover’s favorite sport, he is an all-around athlete. During school he



Kody Conover with his parents

played basketball, baseball and racquetball and was a member of the high school’s bowling and golf teams.

Kody’s interest in golf began when he was barely three years old. His father played in the Golf Channel Am tour. “Someone gave Kody a set of plastic golf clubs. By the time he was ten, he would spend hours on the golf course following his daddy around,” recalls Ms. Conover.

Today, Kody spends a great deal of time practicing his game in Las Vegas, Nevada where the Conovers own a second home. “The weather here in Utah only allows him to practice for maybe three months of the year,” explains Ms. Conover.

And practice, according to Kody, is the key to success. “You have to practice hard, stay focused, get lessons and you have to love the game to be good,” he says. “You must practice all parts of the game with the most practice on the short game.” The young Mr. Conover believes that having Down syndrome may be an asset



where his game is concerned. “It may help me to stay focused and have patience,” he explains. “You must believe in yourself to be good at anything you do.”

The senior Mr. Conover agrees. “Every day he gets better. Kody was raised to be always positive. We don’t say can’t in our family. There is nothing we can’t do.”

Clifford Conover is not just Kody’s dad, he is also his caddy. “My caddy is an important part of my game” explains Kody. “My caddy is old but awesome,” he quips. “He practices with me and takes me golfing. He is my daddy and I love him. I do get a little nervous before a tournament game, but my caddy helps me not to be nervous.”

Golf is just one aspect of Kody’s life. When he is not practicing or competing in a tournament, he is working at the family owned laundromat in Roosevelt, Utah, five miles down the road from the family home. “This is something that Kody will be able to do for the rest of his life,” says Ms. Conover. At age 90, Ms. Conover’s father Mario Croce, known as Papa, works at the laundromat each morning with his grandson.

“Kody has been a blessing to our family,” says Kody’s mother. “When we moved to Utah we brought my mother-in-law with us, and then, three months later, my parents moved here too. It is really nice when you bring your family home.”

Although work in the laundromat and golf take up a good portion of Kody’s time, he finds room for other interests. “He loves to dance, and he loves music,” says his mom. “On his 21st birthday he wanted to go dancing, so that is what he did. He’s a chick magnet.”

“Golf is my passion,” remarks the younger Mr. Conover. “I enjoy playing with friends, getting birdies and winning. My goal is to play in the Masters.” About life in general Kody Conover is an optimist. “Remember,” he states, “it will be okay.” ■



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On the Course



“We couldn’t have asked for a better day,” said Harold Peterson, President, ARC Foundation Board of Directors and Chairperson of the Golf Classic. “The golfers had a great time for a great cause, and the course at Paramount Country Club is superb.”

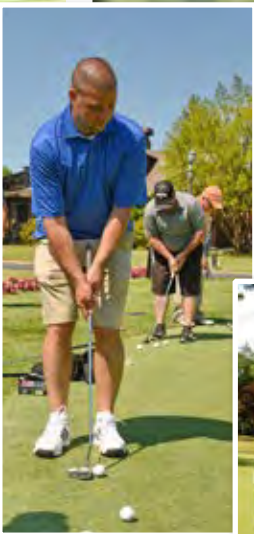
The 31st Annual Golf Classic included breakfast, on-course refreshments, a cocktail reception, a gourmet dining experience, door prizes, gifts, a silent auction and a video featuring Kody Conover, a golfer with Down syndrome (See story page 9).

ARC Chief Executive Officer Carmine Marchionda thanked all of those in attendance. He offered a special note of gratitude to the volunteers who worked tirelessly to make the day a success. “This fundraiser brings together many wonderful people in a show of commitment to ARC of Rockland. As far as ARC is concerned, everyone involved in this event scored a hole-in-one.”

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Advocating for People with Down Syndrome

NDSS Takes the Lead

With 375 affiliates nationwide, the National Down Syndrome Society (NDSS) is a repository of valuable information for professionals and lay people alike.

Founded in 1979, the mission of this organization “is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome,” says NDSS President Sara Hart Weir. “We are focused on breaking down barriers that still exist.”

One of the primary methods of advocacy is the NDSS Buddy Walk® program designed to create awareness across the world. Some 275 Buddy Walks take place in communities across the country throughout the year.



“We are a lot further along than we have ever been, but we still have a lot more to do as an organization and as a society.”

—Sara Hart Weir

“People with and without Down syndrome, family members and community leaders come together to celebrate and advocate for people with Down syndrome through our Buddy Walk® program,” explains Ms. Weir.

NDSS is privately funded through contributions and special events. Approximately three percent of proceeds from local Buddy Walk® events go to NDSS’ National Advocacy & Public Policy Center in Washington, DC.

“There are people with Down syndrome who are going to college, working, living independently, getting

DOWN SYNDROME FACTS

Printed with permission from the National Down Syndrome Society (NDSS) website.

- Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- There are three types of Down syndrome: trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4%, and mosaicism accounts for about 1%.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies in the United States is born with Down syndrome—about 6,000 each year.
- There are approximately 400,000 people living with Down syndrome in the United States.
- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer’s disease, childhood leukemia and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.
- A few of the common physical traits of Down syndrome are: low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.

married—doing everything that everyone else does. To make sure this message is heard,” says Ms. Weir, “we advocate at all levels of government.”

When it comes to employment, NDSS is determined to push for the development of a system of incentives. NDSS spearheaded the advocacy effort and played a significant role in the passage of the *Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act*. The ABLE Act was signed into law on Dec. 19, 2014. The Act amends the Internal Revenue Service Code of 1986 to create tax-free savings accounts for people with disabilities. The accounts allow individuals to save their own money while retaining government benefits.

Ms. Weir began her career with NDSS as a volunteer. She became a staff member in 2012 and took the helm of the organization in December, 2014. She is proud of recent strides made in the realm of inclusion for people with Down syndrome.

“We are a lot further along than we have ever been, but we still have a lot more to do as an organization and as a society,” remarks Ms. Weir. “Expectations for people with Down syndrome should be extremely

- Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to lead fulfilling and productive lives.

high. That is why we advocate in every state capital in the country and Washington D.C., and that is why we work closely with local affiliates to ensure that everyone has a voice to advocate for issues that really matter to individuals with Down syndrome—access to housing, competitive employment, inclusive education and healthcare — the support systems that are really important.”

To learn more about NDSS visit www.ndss.org. ■

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ARC HealthResources

Emphasis on Individuality

People with Down syndrome are no different from the rest of the population, in that their medical issues are as varied as their fingerprints, and their healthcare needs change with time.

It is true that, on the whole, there are some health issues that are more common in a certain percentage of people with Down syndrome. By the same token, there are some conditions for which people with Down syndrome have a lower risk than their peers. Moreover, advances in healthcare have greatly enhanced the length and quality of their lives.

Physical Health

Dr. Galit Sacajiu, Medical Director of ARC HealthResources at ARC of Rockland, discusses some of these health issues and the improving outcomes. For example, she says, “Close to 50% of children born with Down syndrome have cardiac defects. But the vast majority can now have the defects surgically repaired during the first year of life. That is probably the most important medical development to extend lifespan.”

Low muscle tone is another health concern, preventing people from being active throughout their lives. That can now be addressed by ongoing therapy. “We refer patients to physical therapists, occupational therapists and speech therapists to provide the kind of augmenting environment that will assure the best quality of life,” says Dr. Sacajiu.

Often, though, the low muscle tone, combined with endocrine conditions such as hypothyroidism, lead to obesity. “One of the things we focus on with patients who have Down’s is developing a healthy lifestyle and good eating habits,” she says. “We encourage individuals to make their own healthy choices. If they



Dr. Russell Tobe and Dr. Galit Sacajiu

lose a few pounds and are making strides, it is really their own accomplishment. We work with them to find out their dietary habits, encourage them to keep food diaries and to engage in specific physical activities like walking laps in the gym and using stationary bikes. I think these are among the most important interventions we can make.”

Lengthened life expectancy brings its own health issues related to aging. “In the early 20th century, people with Down syndrome rarely lived passed adolescence. Now, many live into their late 60s and even into their 70s,” says Dr. Sacajiu. “That presents challenges for primary healthcare providers, because we don’t have a lot of clinical studies of older adults with Down syndrome. We have to find our own way, while communicating with others in the field.”

What is being learned is that certain age-related issues may be more significant among people with Down syndrome. Arthritis, for example, can be more common, as is osteoporosis, notes Dr. Sacajiu. According to an article which appeared in the September 30, 2014 issue of the *bmj* (formerly known as the *British Medical Journal*), the incidence of long-bone fracture is reported to be as high as 55% in people with Down syndrome.

Certain cardiac conditions may also be a problem. “Even though so much progress has been made in repairing congenital heart disease, other issues such as valve disease can develop later in life,” Dr. Sacajiu explains. “We also have to be aware of early signs

of congestive heart failure. In some cases, I refer the patient to a cardiologist and work directly with the cardiologist to monitor medications and determine whether surgery is necessary.

“People with Down syndrome are more prone to pulmonary infections such as bronchitis and pneumonia, and these infections can drag on for a longer time than in the rest of the population,” states Dr. Sacajiu. The *bmj* article notes that pneumonia is the leading cause of hospitalization for people with Down syndrome, second only to congenital heart disease as a cause of death. Further complicating things, says the article, gastroesophageal reflux and difficulty swallowing are common and may cause a decline in physical and social activities.

Such multiple health issues could result in reduced mobility and ultimately the need for a wheelchair.

“People with Down’s usually develop independent, active lives and to suddenly not be able to participate in those activities might be very difficult for them and their families,”

Dr. Sacajiu comments.

The news is brighter on other health fronts, though. The *bmj* article notes that Down syndrome can also imbue the individual with certain physiological strengths. Adults are at lower risk for most solid tumors and have a decreased risk of hypertension.

Mental Health

As pointed out elsewhere in this magazine (see pages 38, 40, 42), Down syndrome is associated with an increased risk for the early onset of Alzheimer’s disease, but there are other related mental and emotional issues.

“About 50 percent of people with Down syndrome will have a mental health diagnosis at some time in their lives,” says Dr. Russell Tobe, Director of Psychiatric Services for ARC HealthResources.

“The things we see very early on in their lives include ADHD and sometimes autism spectrum disorders,” he says. “Once they are a bit older,

maybe during puberty and early adulthood, anxiety is a common issue. We can see generalized anxiety disorder, in which the individual worries about many different things, and sometimes we see more OCD—obsessions, compulsions and mood disorders.”

“People with Down syndrome are very attuned to their environment and their social relationships, so any changes in routine—the death of a family member, a residential or program change—are more likely to trigger anxiety and depression than would be the case with other individuals.”

Many of the physical issues associated with Down syndrome can be linked to psychiatric issues, Dr. Tobe continues. “Medical issues can cause pain, impact sleep (see page 20) and affect how the brain works. Treatment for mental health issues always starts with a careful evaluation to determine whether there are medical issues that apply, which would be treated by

the primary care physician. Otherwise, we provide the same treatment that any patient would receive.

Cognitive behavioral therapy or supportive

psychotherapy can be helpful. Sometimes medications are used to treat anxiety, OCD or depression, especially when the condition interferes with daily functioning or results in thoughts of suicide,” Dr. Tobe explains.

Both Dr. Tobe and Dr. Sacajiu emphasize the importance of early medical evaluations, enabling primary care providers to determine whether new issues are arising or an individual’s condition is deteriorating. It is especially helpful to choose physicians who are familiar with Down syndrome and are comfortable treating individuals with intellectual disabilities.

“Currently, most teaching programs for healthcare professionals provide little to no training in caring for people with developmental disabilities,” notes Dr. Sacajiu. “But it is important to find those who are comfortable in treating individuals with Down syndrome and are able to be their voice and their advocate.” ■

“About 50 percent of people with Down syndrome will have a mental health diagnosis at some time in their lives.” —Dr. Russell Tobe

Getting A Running Start

At Prime Time for Kids, Inclusion is no Illusion for Youngsters with Down Syndrome

The world has opened its doors to people with developmental disabilities. Men and women with Down syndrome are increasingly accepted and integrated into society as a whole and are taking on roles and responsibilities.

At ARC of Rockland’s preschool program, acceptance and inclusion have been central goals for more than 50 years. From its inception, Prime Time has been a place where children with and without disabilities can play and learn, gaining the skills and self-confidence that last a lifetime.

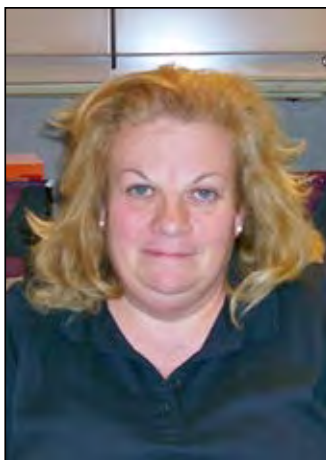
“It’s nice to see that the world is finally catching up,” says Donna Bogin, Assistant Director at Prime Time for Kids. “More and more, employers are hiring people with disabilities. People with Down syndrome are featured in commercials for major corporations such as McDonald’s, TJ Maxx and Mutual of Omaha. A young woman with Down syndrome is now a popular runway model. There was even a new reality TV program on the A&E channel called *Born This Way*, featuring seven young adults with Down syndrome and following them day-to-day as they pursue jobs, enjoy active social lives, and engage in a variety of hobbies and activities,” she notes. “It shows how far we, as a society, have come.”

Ms. Bogin has been with Prime Time for 25 years and has watched this evolution with great interest, although, “In some ways, the approach to treating pre-

schoolers with Down syndrome hasn’t changed over the years, because the disability issues haven’t changed,” she explains. “When children with Down syndrome are first born, the primary issue is usually physical development. They tend to have low muscle tone, and some babies have feeding issues. The cognitive delays start to appear at about six months.”

Years ago, infants with Down syndrome were often placed in center-based programs. But now, the emphasis is on treating infants in their natural environment, usually at home. Through ARC of Rockland’s Early Intervention Program, based on a child’s needs, a team of specialists are available to visit the child’s home.

This team could consist of a Special Educator, Physical Therapist, Occupational Therapist, Speech Therapist or Family Trainer who provide



“It is nice to see the world is catching up. More and more people are hiring people with disabilities.” —Donna Bogin

services in the early stages of life. They work on basic cognitive skills, gross and fine motor issues, expressive and receptive language as well as activities of daily living, including feeding skills. “We also encourage and train the parents to participate in these sessions, so that they can take over the tasks when the professionals are not there,” notes Ms. Bogin. “For example, parents can help the infant in tracking, reaching for objects, playing Peek-a-Boo and providing tummy time. We are not only treating the child, but also assisting the parents—and

in many cases grandparents and older siblings—in learning how to treat the child.”

Between the ages of two and five, the youngsters may come to the Prime Time for Kids Early Learning Center where they interact with schoolmates who may or may not have disabilities. Activities at Prime Time usually kick off with Circle Time—a morning meeting at which the youngsters discuss the day of the week, the weather, the day’s schedule and in some cases, recite the Pledge of Allegiance. Following that, they may visit the Prime Time playground for gross motor activity, attend weekly Music Therapy, make use of the iPads in the Tech Center and join in small and large group activities for Pre-Readiness Skills, which prepare them for kindergarten.

“In the past, after preschool, many of these children entered a Board of Cooperative Educational Services (BOCES) school for children with special needs. Today, parents are increasingly looking to have their kids mainstreamed. In fact, more and more colleges are requiring all Elementary Education students to take at least 12 credits in Special Education, and many schools are looking for teachers who are dually certified in Elementary and Special Education, because the number of children with special needs who are integrated into the public elementary schools has increased greatly,” says Ms. Bogin.

Over the 25 years that Ms. Bogin has been there, more than 100 youngsters with Down syndrome have passed through Prime Time for Kids Early Learning

Center, and she takes great pride in watching their development and accomplishments as they enter adulthood. She cites a few examples, including Katie Foreman (see story page 32), a young woman who lives in an ARC home and is employed at a LEGO store.

Some youngsters come back to ARC for Prime Time Plus, its summer respite program, and others attend Club ARC, the summer camp program. As young adults, they can participate in *ARC in Motion*, which matches participants with like-minded peers and provides them with opportunities to engage in volunteer work and recreational activities throughout the community. Many former Prime Time students receive job training and placement through ARC Career Services.

“Prime Time for Kids Early Learning Center provides children with the foundation,” says Ms. Bogin, “But that’s just the beginning. ARC of Rockland offers these youngsters a lifetime of friendships, skills and supports.” ■

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Down Syndrome and Sleep

The Link to Learning

“In our culture, people don’t often recognize sleep as being an important issue.” This, despite the fact that “Sleep plays a significant role in learning,” says Jamie Edgin, PhD. Dr. Edgin is an Assistant Professor in the Cognition and Neural Systems Program in the Department of Psychology at The University of Arizona where she is affiliated with the Sonoran University Center of Excellence in Developmental Disabilities (UCEDD).

“The majority of my group’s work concerns the unrecognized sleep issues that affect people with Down syndrome,” states Dr. Edgin. “Within the last five to ten years, research has made it clear that the brain does not shut down when we sleep. When we sleep, our brain enters into well-defined stages of learning. Specifically, regions of the brain engage in levels of communication that don’t occur as efficiently during the day.”

Dr. Edgin points out that her initial studies focused on school-age children with Down syndrome who were diagnosed with sleep apnea. When compared against the results of children with Down syndrome who did not have sleep apnea, the studies revealed a nine point difference in verbal IQ. The findings were published in *Developmental*



Medicine and Child Neurology in 2014. Her studies have since expanded to include younger children, including toddlers and infants as young as six months.

Although sleep studies have long been performed in laboratory settings, the studies undertaken by the Edgin laboratory are conducted in the child’s home. “We are not a clinical group, but we are psychologists,” Dr.

Edgin says. She notes, however, that medical doctors are associated with the sleep research being undertaken by her group.

The choice of the home setting was selected for the “comfort level of the study participants,” says Dr. Edgin. The child’s

“We have learned over time, if a child continues to not sleep well, he or she may show cognitive deficits.”

—Jamie Edgin, PhD

sleep is monitored over the course of a nap or overnight. “We measure respiratory activity, oxygen reduction, breathing, and air flow—how much that is constrained during sleep.” EEGs and ECGs provide vital information on the child’s sleep states. The results are compiled to give the researchers a picture that includes the depth and consistency of sleep. “We have seen up to 30 apnea events per hour where the child’s breathing pauses for ten seconds or longer,” states Dr. Edgin. “We have learned that over time, if a child continues

to not sleep well, he or she may show cognitive deficits. Primarily, we see that sleep influences language learning and the building of memories for vocabulary words.”

“One of the things we are trying to emphasize is the extent of sleep problems among those with Down syndrome.” Dr. Edgin points to studies conducted by Sally R. Schott, MD, regarding the medical side effects of sleep apnea. These studies have shown that “At least 50 percent of toddlers with Down syndrome show sleep apnea. In typically developing children, five or six percent have sleep apnea.”

Sleep occurs in cycles, beginning with Stage 1, or lighter sleep. “During Stages 2 and 3, large, high-amplitude brain waves reflect pools of neurons firing together in synchrony—a phenomenon indicative of active learning,” explains Dr. Edgin. “Researchers believe that Stages 2 and 3 are linked to declarative knowledge consolidation. When the brain gets done what it needs to get done, the person then moves into REM rapid eye movement (REM) sleep—the phase most involved in dreaming.”

It may be difficult for parents to know whether or not a child has sleep disturbances, given Dr. Edgin’s findings that parents’ reports of sleep don’t always correlate with their children’s actual sleep quality. This is why most medical professionals working with children with Down syndrome suggest early screenings and monitoring for sleep apnea (by 4 years), even if parents are not concerned. “Hearing a child snore or gasp during the night could be an indicator of sleep apnea. Says Dr. Edgin, “It is not the amount of sleep that matters, but the fragmented quality of sleep—the fact that people with sleep apnea may not fall into a deeper stage of sleep—that is cause for concern.

Should parents suspect a problem, Dr. Edgin recommends a consultation with the physician who will help to design a treatment plan. In some cases, medical interventions such as the removal of tonsils and adenoids may be recommended. In other situations, the use of a CPAP, or (continuous positive airway pressure), might be helpful.

“On a positive note, sleep is treatable,” says Dr. Edgin, “and the methods of treating sleep apnea are increasingly becoming available across the lifespan.” ■



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The Ties That Bind

Large Family with Big Hearts

Kathy Nowak is the Director of Nursing for ARC of Rockland. She and husband Joseph, a retired NY State Police Officer, are the parents of ten, including three children with Down syndrome.

“As a young nursing student, I fell in love with infants known as border babies—babies who would come to the hospital because of abuse or neglect or disability and would board there until they were adopted or returned to their families.”

The memory of one such child haunts her still. “I had never seen a baby this beautiful. He had arrived at the hospital in October because of a failure to thrive. I would visit him before classes, at lunchtime and after school.” During the months that Ms. Nowak helped to nurture the boy, he became stronger—more robust. “In April, when no placement had been found for him, he went back to people who hadn’t cared for him in the first place. Right then, I knew that once I had the ability, I would take care of children that others could not or would not keep. Years later, when Joe and I moved to Rockland and bought a five-bedroom house, I said, ‘I can fill those rooms. We’ll be foster parents.’” Fortunately, Mr. Nowak agreed. Ten children later, the Nowaks have kept their promise.

Fostering

The couple’s first foster child had Down syndrome. “He was born to an Orthodox Jewish family,” recalls Ms. Nowak. “We kept a kosher home for that little boy.

“The moment after he came into the world, the doctor told his mother that she had given birth to a ‘Mongoloid baby.’ (A terrible term, thankfully, no longer in use). In fear and anguish, the young mother

went back home to her other children—leaving the baby to foster care. During the year and half that the boy lived with the Nowaks, the child’s biological parents, grandparents and siblings visited frequently—playing with the little boy and getting to know him. Ultimately he went home. “It was a perfect transition,” recalls Ms. Nowak. The boy knew both of his families. Today, Ms. Nowak says, he is a beloved member of his birth family. He has many siblings and works in his father’s business.

Caring for their first foster child taught the Nowaks several lessons. “I found that children with Down syndrome are no different from other children. They are slower, but not different.” Ms. Nowak also knew that she would never again be able to give back a child. “We kept our foster certification with the addendum that we would only foster a child with the intent to adopt.”

Of their ten offspring, four are adopted. Two other sons, Lu and Liem were among the Vietnamese refugees known as *boat people*. “We took the boys in 1980 when they were teenagers.” Both are now married and the fathers of one son each. “Lu’s oldest son is in Harvard—our grandson is in Harvard,” smiles Ms. Nowak. The young men and their families remain in touch and visit the Nowaks on holidays. Lu is a CPA in Orange County, NY. Liem and his family live in Houston, Texas where he is manager of a golf course. The men’s sisters and father eventually came to the United States. Their mother died just before receiving permission to leave Viet Nam.

Proud Parents

The Nowaks are the birth parents of Adam, Sean, Deidre and Ryan. Ryan, of Orange County, NY works for the Thruway Department. He and his wife are parents of a daughter. Adam lives in New City and also works for



Evelina, Alana, Diedre, Mark and Tara with their parents and pet dogs

the Thruway Department. Sean, in the security business, lives in the family home in Congers, NY. Deidre, of New City, is a Special Education Teacher. Tara, Mark and Alana, all of whom have Down syndrome, and all of whom are adopted, live in the family home. Evelina, the Nowaks' fourth adopted child, now residing in the family home with her infant daughter Anna Maria, had previously lived in Palm Beach, Florida, where she volunteered at an animal shelter.

Added to the lively family mix are two German shepherds and four Yorkshire terriers.

Kathy Nowak is both a realist and an optimist, and, while she says she is not religious, she admits to having a "spiritual nature." The Nowaks were already the parents of Ryan, Adam and Tara when "Joe had a dream that we would have a son named Mark." At a prayer service the family attended at the behest of Mr. Nowak's mother, the clergyman looked at me and said, 'Where is your son Mark?' When he said that, I started to cry."

How the clergyman knew about Mark remains

a mystery. "But who am I to tempt fate?" asks Ms. Nowak. Following the prayer service, she went home and called Social Services to ask if they had a baby with Down syndrome available. And if so, I said, 'We want him.' They called me back the next day." A baby boy with Down syndrome had been left unnamed in a hospital. "He was born on the Feast of St. Gerard. St. Gerard is the patron saint of expectant mothers," explains Ms. Nowak. "We named him Mark Gerard."

Bumps in the Road

Life for the Nowaks has not been without its trials. "We brought Tara home from the hospital when she was three-days old. At six-months old, the sack around her heart had filled with fluid and her heart was being crushed. I was pregnant with Deidre at the time. We took Tara to Columbia in Manhattan. Joe drove like we were in a police car," recalls Ms. Nowak. Tara survived and thrived following successful open heart surgery.

Mark has twice had leukemia. "Kids with Down

Continued on page 24

The Ties That Bind

Continued from page 23

syndrome are three times more likely to develop leukemia,” remarks his mother. “The drugs he took during the bouts with the illness affected his knees. He needs knee replacements, but he still plays golf and baseball, and he manages to slide into base and win Special Olympics gold for running.”

Tara has sleep apnea and chronic allergies. Both she and Alana are on thyroid medications and have had pneumonia multiple times, as has Mark.

To the Nowaks, however, the illnesses are simply bumps in the road. “I have to say we have a good life—a happy life,” says Ms. Nowak. “Our children are good natured. But contrary to some preconceived notions about people with Down syndrome, they are not all gentle, kind souls,” notes their mother with a smile. “Tara is nothing but a ball of attitude. Alana is a social butterfly and Mark is hooked on his iPad.”

All three of the Nowak children with Down syndrome attended preschool. “Tara attended ARC’s Prime for Kids before it was called Prime Time.” Tara and Alana are graduates of Clarkstown High School. Mark is a graduate of BOCES.

Friendship

On the subject of inclusion within the school setting, Ms. Nowak sees benefits and drawbacks. “The modeling was good—watching, imitating and learning from students who do not have disabilities.” But at the time, Ms. Nowak says, “There was little significant interaction among the students with and without disabilities. Would someone invite the girls to eat lunch

at their table?” she asks rhetorically. “Would anyone say, ‘Come join us at a club after school?’” Ms. Nowak notes that her children are in their thirties now. “I know younger people with disabilities who have had more inclusive experiences in school.”

Although her daughters attended high school dances, they were not typically part of the larger student body. “Now, though, they love to socialize. Alana, Tara and Mark are all enrolled in ARC’s Franklin Square post high school campus in Pearl River. While they are members of different groups within Franklin Square, all three are happy with the activities in which they are engaged. In addition to the educational, recreational and volunteer opportunities they enjoy during the weekdays, they participate in ARC’s Recreation Program. On most evenings or weekends, they are out and about at movies or street fairs, swimming, bowling, playing golf or baseball, taking Zumba classes, visiting sites of historical or recreational interest. “The main thing is, they are hanging out with their friends,” states their mother. And while they have not articulated the fact in so



Kathy and Joseph Nowak

many words, “Their best friends have disabilities. I think being with their peers has given them confidence, allowed them to say to themselves, ‘I am with people who like me and talk to me and value my opinion. I choose to be here with these people. This is my choice.’”

“If you could be a fly on the wall and watch them with one another you would see how accepting they are. If a person is in a wheelchair, and if that person needs a sweater or a tissue, a friend will just get what is needed and move on. I’ve seen someone fall during a race at Special Olympics, and I’ve watched one of the other

Kathy Nowak holds a Bachelor’s degree in Nursing from Dominican College and a Master’s degree in Nursing Education from CUNY Lehman. Her career has included positions in numerous hospitals and agencies helping people with intellectual or other developmental disabilities. She has worked in emergency rooms, in neonatal intensive care units, and she has taught at several colleges, including Concordia College, Bronxville, NY; The College of Mount Saint Vincent, Bronx, NY and Dominican College in Blauvelt, NY.

runners go back to help the runner to his feet.”

Looking Ahead

Whether it concerns the option of one day living in a community residence, a potential employment opportunity or involvement in an area event, whenever possible, the senior Nowaks defer to their children’s wishes. And yet, Ms. Nowak says, “I worry—always. I am over-cautious. I fear that Mark, Tara and Alana are vulnerable, that someone could take advantage of them. I’ve bought them all cell phones,” she states. “Mark leaves his at home. The girls carry theirs, but forget to charge them.”

As she looks towards the future, Ms. Nowak says, “I want not to have to fight so hard for funding so that people who need a little help can do better. I want for Alana, Mark and Tara what I want for all of my children. I want them to be happy. I want them to be able to choose what they want to do, to live where they want to live, to be productive.” And then, with a twinkle in her eye, she adds, “I want a magic wand.” ■

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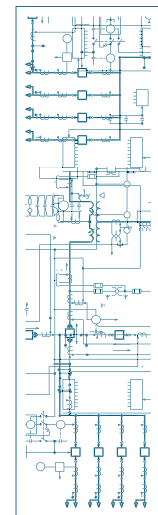
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Orange & Rockland

EVERYTHING
MATTERS

Audrey McCue

Why Giving Matters

When their daughter was born with Down syndrome 62 years ago, the pediatrician told the young couple to ‘put her away.’ But Audrey and George McCue (he passed away in 2005) did not take that advice. Instead they brought Mary Ellen home to be reared with two older brothers, and later, two younger brothers. “She was treated like any of the other 20 children on the block,” recalls her mother.

Still, a loving family and caring neighbors could not provide all that Mary Ellen needed. It was the 1950s. The concept of inclusion was a distant dream. Education, employment, recreation and housing for people with developmental disabilities were in their infancy. ARC of Rockland was a fledgling organization created by a small cadre of parents. Regular trips to Albany to advocate for funding were the norm. The battles for services were fierce. And always, the parents, including the McCues, were on the front lines.

Much has changed in the generations since then. Today, parents of children with developmental disabilities count on agencies such as ARC of Rockland to provide services and supports throughout their children’s lives. “I feel that parents don’t always appreciate what we have,” says Ms. McCue. “They want more and more. But there is no money. Even if families understand that the government has cut back on funding, too many people leave the fundraising to somebody else. Really, it is the obligation of every parent and every member of our chapter to help out to the best of our ability—financially or otherwise.



Audrey and Mary Ellen McCue

“At some point in our lives, we have to establish priorities and our children are a priority. And sometimes, a priority includes a little financial support. If we can’t give 50 dollars maybe we can give five dollars. But we have to give something.”

Although dollars matter, giving comes in various forms. The McCues became members of the ARC of Rockland Board of Directors in 1955, and one or the other

often served as an officer in the ensuing years. Ms. McCue is particularly adamant about the obligations incumbent upon members of the Board. “I think it is our job to be out there in the community to let people know about ARC of Rockland.” When ARC of Rockland became the owner of Strawtown Jewelry in New City, Ms. McCue was there for opening day. When ARC calls for volunteers at an event, she is among the first to sign up. “I do this not because I am wonderful. I show up because I am interested and because my daughter lives in an ARC residence and is enrolled in ARC’s day programs. We have to show the ARC staff who are working with our children that we care. Attendance at ARC functions that are not necessarily fundraisers is a way of showing support and thank you to staff. To my mind, there is not enough money to pay the people for the work they do. They are worth millions. We need to say ‘please’ and ‘thank you’ more often to the people who take care of our children the way they take care of themselves.”

Among the ARC leaders deserving of praise, Ms. McCue points to Harold Peterson, President of the ARC Foundation Board of Directors. “Harold is a very unusual and wonderful man. He is the kind of person you only hear about once or twice a year, but we would never be this far with fundraisers such as our *Golf*

Classic and A Taste of Rockland without Harold. A lot of people talk, but don't act. Harold does not have a family member with a disability, but he acts on our behalf. More people should take a lesson from Harold."

To new parents of infants with Down syndrome or other developmental disabilities, Ms. McCue says, "Take your child and love him or her and raise that child normally. Allow your child to play with other children. They learn from other children. Don't overly protect your child. Parents today are so afraid of everything. When you are a new parent of a child with a disability, you have to pull yourself together and do something. You have to treat children with dignity and you have to have a little discipline. Become involved in ARC of Rockland. It is the parents who have built ARC of Rockland and the parents who will keep it strong. We've done a lot of good things in the past. Now it is time to look ahead and do wonderful things for the future." ■

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Brotherly Love

In Support of Siblings

Michael McCue has fond memories of his childhood. As the oldest of five, he remembers roughhousing with his three brothers, family outings, and of course, taunting his little sister Mary Ellen, who was the only girl among all these boys. The fact that Mary Ellen has Down syndrome never seemed to influence the boys' behavior.

"I don't think that in our household, we gave Mary Ellen a break because of her disability," says Mr. McCue. "She was treated like the rest of us. We lived in a Cape Cod-style house and her bedroom had two doorways. My brothers and I ran through there and drove her crazy. We would grab her favorite red-handled spoon and not let her have it. In other words, we taunted her the way we taunted each other. We were all very close."

Today, the siblings are all grown, but their devotion to their sister has not diminished. Michael is 64 and lives in Pearl River; Laurence is 63 and lives in New City; Mary Ellen is 62 and lives in an ARC residence; Kevin, 54, lives in Tucson and Bill, 52, lives in Brooklyn.

For decades, ARC of Rockland has been as much of a presence in their lives as their own family members. "My parents were among the founders of the organization more than 60 years ago," Mr. McCue explains. "ARC has helped Mary Ellen to live a great life. She has staff people who are devoted to her, she does volunteer work in the community, and she has a better social life than I do."



Mary Ellen and Michael McCue

But Mr. McCue, Director of the Public Library in Teaneck, N.J., has discovered that just voicing his appreciation isn't enough. He needs to be a part of Mary Ellen's world, and the world of ARC of Rockland, in a much more personal way.

"At first, I was busy with my own

life and my own kids. My parents were so involved with ARC that I didn't feel the need. My mother is still on the Board. But when my children got older, and after my father passed, I decided I should ramp up my activities with the organization."

"I guess my first real involvement with ARC started with *A Taste of Rockland*, an annual fundraising event initiated by the Howard sisters many years ago," he recalls. In 1995, Catherine Howard, along with daughters Theresa Howard, Patricia Maldonado and JeanMarie Maldonado, helped create and develop *A Taste of Rockland*, which over the years, has become a showcase of delicious culinary fare from the area's top restaurants. "They recruited me because they wanted to get siblings involved. For my first assignment, they sent me somewhere in the Meadowlands to spy on another organization that was having a similar event so that I could learn all the ins and outs," he says with a laugh.

He became a member of *A Taste of Rockland* Planning Committee and a coordinator of the year-round project to acquire unique and fun items for the event's Silent Auction. But his involvement does not end there. He is now First Vice President/Asst. Treasurer of The ARC Foundation of Rockland's Board of Directors.

He also started going to ARC’s recreational bowling on Sundays at Hi Tor Lanes in West Haverstraw. “The older adults, ages 30+, bowl in the morning. We pretty much take over the whole alley. But there are only about half a dozen parents and siblings who attend. In fact, I may be the only sibling. I just try to be a big brother to some of the participants. By now they’ve gotten so used to seeing me there that if I don’t show up, the following week I have to prove that I wasn’t just sleeping in,” he says appreciatively. “It’s a very enjoyable couple of hours on a Sunday morning.”

Mr. McCue has also become increasingly familiar with the workings of ARC of Rockland and the challenges faced by the organization. “I think a lot of people have come to take ARC for granted,” he says. “But going through the funding process with Carmine (ARC of Rockland Chief Executive Officer Carmine Marchionda) really opened my eyes. Government funding has been cut back dramatically, and ARC can’t

provide all the programs and services without our help.

“Moreover, people with developmental disabilities are living longer. Life expectancy has greatly increased in the last half century. Our relatives with developmental disabilities are starting to outlive their parents. If siblings step up, they can fill the void,” Mr. McCue points out.

The need, however, isn’t just a financial one. It is also a personal one. “Just because a person has become 21 and is technically an adult, doesn’t mean he or she doesn’t need emotional support and friendship,” says Mr. McCue. “When the parents are no longer around, what happens on birthdays, Thanksgiving, Christmas? Having family to be with is meaningful. I’m very happy to do that for Mary Ellen. My wife, my children and grandchildren are also very supportive. I hope more and more siblings will feel the same way and remain an important part of their relatives’ lives, and the life of the organization that has done so much for us all.” ■



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Accentuating the Positive

Siblings of People with Down Syndrome

Dr. Brian Skotko takes a special interest in the siblings of people with Down syndrome. He is Co-Director of the Down syndrome program at Massachusetts General Hospital, co-author of several books on the subject of Down syndrome and the brother of Kristin Skotko, a woman with Down syndrome.

“Kristin has been a life coach for me,” says Dr. Skotko. “It is because of her that I really became involved in the disability advocacy community and decided to dedicate my professional career and energies to giving back to people with Down syndrome.”

A life-changing moment occurred for Dr. Skotko when he was just 18. He and other family members were seated in the audience during a traveling production of the Broadway hit *Grease*. The show had come to the Skotkos’ hometown of Cleveland, Ohio.

“Kristin loved *Grease*,” recalls Dr. Skotko. Before the show began, the audience was given the opportunity to dance on stage. “I was just out of high school. The last thing I wanted to do at that time of life was to go



out with my parents. And I definitely did not want to be on stage. The very first thing Kristin wanted to do was be up there dancing.”

Dr. Skotko recalls his mortification when his parents insisted that he follow his sister and convince her to come back to her seat. “Right then, when I was on that stage, hating everything that was happening, I looked at her face and I saw sheer, utter joy. And in nanoseconds, I went from feeling anger to feeling the most raw,

“I tell brothers and sisters, they can choose when and how to advocate. To advocate every day becomes exhausting.”

—Dr. Brian Skotko

pure love. That is what a sibling with Down syndrome can do for us. In that moment, I looked at my sister and knew that she was not going to sit back down in her seat, that no one was going to tell her not to be on

stage. And I found myself thinking, ‘Good for her.’”

That epiphany has remained with him ever since. Based upon his research and the research of other professionals, Dr. Skotko notes that “Siblings of people with Down syndrome seem to be distinctively advantaged in life compared with people who don’t have a sibling with Down syndrome. The brothers and sisters of people with Down syndrome are rated as more patient, kinder and more tolerant of differences.

*Dr. Skotko is a Board Certified Medical Geneticist. A graduate of Harvard Medical School and Harvard Kennedy School, he serves on the Board of Directors of the Massachusetts Down syndrome Congress and Band of Angels Foundation. He is co-author of **Common Threads Celebrating Life with Down syndrome**, available through Bandofangels.com, Amazon.com and other online booksellers, and co-author of **Fasten Your Seatbelt, a Crash Course on Down syndrome for brothers and sisters**, Woodbine House.com.*

“Older siblings report that over a lifetime, they have learned deep lessons in how to love, how to find life’s riches in small packages and not the big ones, how to try and try and try again,” states Dr. Skotko. “They have learned that success is often as sweet when you win the bronze as when you win the gold.” It appears that for most brothers and sisters of people with Down syndrome, the ability to problem solve, manage anger, and negotiate successfully are long-term benefits of this unique sibling relationship.

Although his findings strongly suggest that the positives outweigh the negatives, “I don’t want to sugar coat things,” remarks Dr. Skotko. “We have heard from siblings ranging in age from 9 to 60, that there are tough, negative and difficult moments in being the brother or sister of a person with Down syndrome.”

“During the early years, youngsters most often worry about being teased by peers. In the teenage years, they are trying to figure out their own lives. This is a time of some anxiety. Siblings can be irritable around that age. As we get to the older years, we start to appreciate our brothers and sisters. The little pains seem to be forgotten, and we retain warm memories of how the siblings shaped who we are. As we become adults, and we take on concerns about guardianship or financial issues, we worry about how to honor the legacy of our parents after they pass on. In general, we see an early maturation of advocates.”

Advocating for a sibling can be frustrating. “I tell brothers and sisters, they can choose when and how to advocate. To advocate every day becomes exhausting. We have to be able to say, ‘I’m taking a day off,’ and not feel guilty if we don’t correct every person who uses the R word.”

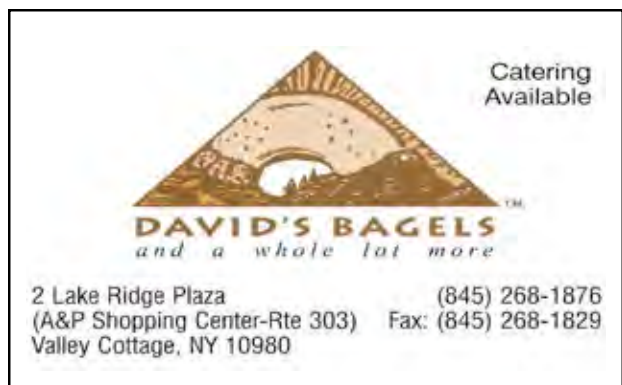
Dr. Skotko recognizes the significant differences among families. “We cannot assume that family dynamics are the same for all people, and we cannot assume that all disabilities are the same. Some siblings of people with Down syndrome will always struggle. We need to make sure that these people get the support and resources they need and the opportunity to talk

when they need to talk.”

Research indicates that long-term opportunities for people with Down syndrome are best “when parents have clear wills, financial plans, and Special Needs Trusts,” notes Dr. Skotko. “And there needs to be an annual clinical checkup of people with Down syndrome—preferably by a clinician familiar with Down syndrome.”

Among his numerous projects, Dr. Skotko is in the process of creating a virtual Down syndrome clinic. “The average doctor may have one or two people with Down syndrome in his or her practice. This secure website that we intend to create will enable a trusted family member to complete a questionnaire. Based upon the responses, the family will receive a one-page set of customized recommendations to take to their primary care physician.” Dr. Skotko anticipates that the virtual clinic will be ready in the next three years.

Where the future of people with Down syndrome is concerned, Dr. Skotko is optimistic. “Having an extra copy of chromosome 21 does not dictate a playbook. We know there is diversity within people who have Down syndrome just as there is diversity within all people. Don’t set limitations—set expectations. Shoot for the stars and if you reach the moon, the moon is a great place to be as well. A new generation of people with Down syndrome is growing up with more access to inclusive education. They are healthier, more respected and celebrated in their communities. I like to say, ‘The best is yet to come.’” ■



Building a Future Brick by Brick

Confucius, the Chinese philosopher, once said, “Choose a job you love, and you will never have to work a day in your life.” It was true when he made note of it more than 2,500 years ago, and it is still true today. Katie Foreman can attest to it from personal experience.

Ms. Foreman, 32, works at The LEGO Store in the Palisades Center. The store is a bright, warm, welcoming place filled with a multitude of colors and happy faces. But perhaps the brightest thing there is the smile on Ms. Foreman’s face. “I love to be here,” she says, as she exchanges a ‘high five’ with store manager Derek Lopez. The fact that she has Down syndrome does not diminish her accomplishments, or her enthusiasm. This is, for her, a dream job that matches her skills with a passion for LEGO shared by her entire family.

“I think Katie got interested in LEGO through her older brother, Jim, who played with them for years,” explains her mother, Jane Foreman. After moving out, he suggested we buy Katie a LEGO Creator Kit. It has assorted LEGO parts from which you can make three different projects. I sorted the pieces for her, and the LEGO instructions are all done in pictures which Katie can follow herself.”

Pretty soon, the young Ms. Foreman caught the LEGO bug and began collecting kits in earnest. “We have tubs and crates full of LEGO in our house: in the garage, under Katie’s bed, everywhere,” says her mother. “I don’t have to help her with them anymore. She buys the kits and after she builds them she gives many of them away to friends and relatives. Now the whole family is into it. I build some things from collections of loose bricks, and when Jim comes home,



Katie Foreman, left, with Elonda Harris

we all build huge projects together.”

The family also started patronizing the Palisades Center LEGO Store on a regular basis. The senior Ms. Foreman, an artist, began painting portraits of some of the employees and giving them as gifts to the people whose images she had captured. It wasn’t long before the staff got to know the family and Katie’s Foreman’s passion.

“We used to engage with Katie in the store on her visits,” recalls Mr. Lopez, the store manager. “She was enthusiastic about LEGO and we realized that she had what we need in an associate: someone who is friendly, outgoing, knowledgeable and would demonstrate the benefits of LEGO sets.”

At the time, Katie Foreman—who lives in an ARC residence—was enrolled in the Pathway to Employment program at ARC of Rockland. An internship at The LEGO Store was arranged, and that internship led to paid employment. “It was the perfect approach to job-finding, a true team effort in which the family, the employer and Katie Foreman herself all played a part in landing the job,” explains Kathy Canter, Senior Director of Employment Services at ARC of Rockland. Ms. Foreman has been working as a part-time Brick Specialist at the store for almost two years now, and both she and her employer couldn’t be happier.

“As we do for all our employees, we developed an

Individual Development Program (IDP) for Katie with the tasks we would help her to learn,” Mr. Lopez says. He understood that, consistent with certain behavioral traits of people with Down syndrome, Ms. Foreman is more comfortable with a set routine. So the staff at The LEGO Store devised a checklist for her. “We started with simple things: hang up your coat, clock in... After she does that, she cleans and dusts the area and fixes the Pick and Build wall, which has 108 types of bricks needing to be sorted by sizes and colors. The brick wall is her favorite job. When it’s running low in certain categories, she knows to notify us. She will then fix the boxed sets on the floor, and if we lack some, she knows to go in the store room to pick up more. We call it *stocking standards*. She also assembles what we call *collateral packs*, marketing packets containing a calendar of upcoming events at the store and a copy of the *Club Magazine* for the kids, which we distribute to customers.

“In an area in which she’s comfortable, Katie is very engaging, as when she talks about *Friends kits*, which are her favorite. When she’s uncomfortable or unfamiliar with a task, we have someone work with her to help her overcome her discomfort,” Mr. Lopez explains.

A visit to the store finds Ms. Foreman busy returning some scattered LEGO bricks, with which customers can play, to an open bin. A little girl approaches and starts picking out some pieces, and Ms. Foreman gives her a big smile and helps her for a time. Then she moves on to arrange some of the stock on the shelves, making sure the boxes are in the right place and moved forward so that customers can see them clearly. A moment later she is behind the counter, helping place a customer’s purchase into a bag. “Have a nice day,” she says cheerfully, as the customer leaves.

Mr. Lopez points out that no one had to ask Ms. Foreman to do each of these tasks. “She now knows what to do and what is needed and moves easily from one area to another. As she progressed on the job, we would take things off the check list, and eventually got rid of it altogether.”

ARC job coach, Elonda Harris, is impressed with how far Ms. Foreman has come in learning the job. “When she first started working here, Katie was afraid to be out front. But we’ve been working on her being independent, and she has made great progress. I have started the process of ‘fading’, which means I spend less and less time with her on the sales floor because by now, she can do the work on her own. At this point, we’re working on time management. She’s always been good at that, but we just got her a wristwatch so she can keep track of her lunch break on her own.”

“It has been a very good first work experience for Katie and has opened her up to pursuing other job experiences,” says Ms. Canter, who expects to be able to place Ms. Foreman at a second part-time job in the near future.

In the meantime, The LEGO Store of Palisades Mall made a YouTube video about the senior Ms. Foreman’s LEGO portraits and daughter’s work at the store. Titled Jane’s LEGO Canvas, the video was aired during last year’s meeting of LEGO Worldwide Managers. It was presented by the Senior Director of LEGO Brand Retail Operations in North America, Kurt Ratchdorf who, on a recent visit to the Palisades Center store, was himself a subject of a Jane Foreman LEGO portrait.

Ms. Foreman has become an inspiration in more ways than one. “Her older brother, Jim, lives in San Francisco and was a bit jealous of Katie’s job,” says their mother. “We recently got a call from him saying that a LEGO store is opening in San Francisco, and guess who’s applying for a job?” ■



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The Evolution of Individual Rights

A young woman with Down syndrome recently won a landmark court battle that has stimulated a national discussion on the issue of guardianship and individual rights.

In 2012, Margaret (Jenny) Hatch was in her late twenties and had been making her own decisions about where to live and work, without a legal guardian. But after a bicycle accident landed her in the hospital, her parents petitioned the court for a form of guardianship that would allow them to make all of their daughter's decisions for her.

Jenny Hatch challenged the guardianship, saying that she deserves the freedom to make her own choices. Ultimately the court agreed that, although she needed help in making decisions, Ms. Hatch's preferences should be taken into account. Some have called this a landmark decision, supporting the right of an individual with a developmental disability to make independent decisions, with support, rather than being forced to accept legal guardianship.

The case marked a turning point for those advocating what has become known as Supported Decision Making (SDM), a new approach whereby a network of supports is created for a person with disabilities, helping that individual to make independent decisions whenever possible.

According to the *Washington Post* (August 2, 2013), the court's ruling highlights "an individual's right to choose how to live and the government's progress in providing the help needed to integrate even those with the most profound needs into the community." In fact, the United Nations Convention on the Rights of Persons with Disabilities challenges the existing system of guardianship and advocates SDM.

It is important to note that the kind of independence

Ms. Hatch sought is not necessarily a good fit for every individual with a developmental disability. "Legal guardianship is still important in many cases. But the conversation has shifted, and parents should be aware of the full gamut of possibilities as their child becomes an adult," says Jacqueline Phillips, Director of Staff Development and Training at ARC of Rockland.

When an individual reaches the age of 18, he or she is no longer considered a minor, and the parents are no longer automatically considered the guardians. Unless the parents file for legal guardianship or other arrangements are made, the individual becomes the sole decision maker. It is therefore important for parents to understand the alternatives and be prepared before the child reaches the age of consent.

Two Forms of Legal Guardianship

To clarify this rather complex issue, Ms. Phillips explains the options:

"In New York State, there are two different types of legal guardianship. Article 17-A Guardianship is a Surrogate Court proceeding which designates a guardian to act on behalf of an individual with intellectual or developmental disabilities after that person has turned 18. This form of guardianship usually gives the same kind of decision-making power that parents have over a child. Article 17-A assumes that the person is not capable of making some or all decisions and is in need of protection."

Parents can fill out and file the forms themselves, without the need of a lawyer. ARC of Rockland provides quarterly seminars on Article 17-A, walking families through the application process. The procedure usually takes several months during which time the application goes through several layers of review.

In New York State, NYSARC Inc. offers Corporate Guardianship under Article 17-A in those situations where there are no family members or others who can



Jacqueline Phillips, Dinorah D'Auria and Alyson Brenner

serve as guardians. “ARC chapters in New York State serve as agents for NYSARC, providing guardianship for those who do not have a legally-authorized decision maker to act on their behalf,” explains Alyson Brenner, Guardianship Coordinator for the Guardianship Committee of ARC of Rockland.

“Some parents plan ahead and designate NYSARC as a *standby guardian*, in the event that they are incapacitated or die. Parents can even designate NYSARC as the *alternate standby guardian*, in case the individual originally chosen by the parents as the alternate guardian also becomes unable to serve,” Ms. Brenner continues. If arrangements were not made before the death of the parents or other guardians, the Medicaid Service Coordinator or other person involved in the person’s life may pursue Corporate Guardianship for the individual. Currently, the Guardianship Committee at ARC of Rockland serves as *primary guardian* for five individuals and *standby guardian* for four.

As the Guardianship Coordinator, Ms. Brenner visits each of the people once a month, sometimes at their community residences and sometimes at their day programs. She receives incident reports, monthly medical reports from Residence Managers and Medicaid Service Coordinators (MSCs), and she attends Individual Service Plan (ISP) meetings. She then shares these reports with the Guardianship Committee, giving them a monthly update.

“The Committee looks at these individuals as family members and makes medical and other decisions

for them as needed,” says Ms. Brenner. “The Committee also receives training on end-of life procedures and works with NYSARC when these situations arise.”

ARC of Rockland, as agents of NYSARC, handles guardianship of the person, mainly healthcare-related issues, but not guardianship of the property. The individual’s basic costs are covered by their government allotted benefits, as with anyone who lives in a community residence.

Some of the funding to support the program comes from the NYSARC Trust. This money may be used for special events, gifts and administrative costs.

The downside of Article 17-A is that the individual with a disability can be completely cut out of the decision-making process, as was the case with Jenny Hatch. “Many families pursue 17-A Guardianship, but when they read the forms and see that it means

When an individual reaches the age of 18, he or she is no longer considered a minor, and the parents are no longer automatically considered the guardians.

their child would have no rights, they reconsider the alternatives,” says Ms. Phillips.

In such cases, another option is Article 81 Guardianship, which refers to Article 81 of New York’s Mental Hygiene Law. “The benefit of this kind of guardianship is that it gives parents the option to choose specific areas of guardianship, pinpointing exactly which decisions are made by the individual with a disability and which ones are made by the guardian,” Ms. Phillips explains. “It is tailored so that the powers granted to the guardian are only those that are specifically necessary to meet the needs of the person with a disability. For example, if the family is concerned that the individual will open a credit card

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Individual Rights

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and get deeply into debt, Article 81 would allow for guardianship on finances only, or healthcare only, while the individual with a disability would still be able to make decisions about where to live and work.”

Many families are hesitant to pursue Article 81 Guardianship because the process is much more complicated and expensive. Unlike the process for Article 17-A, which parents may pursue on their own, Article 81 usually requires the aid of a lawyer and must be granted by the County Supreme Court.

But Article 81 Guardianship can be a stepping stone to Supported Decision Making, allowing the individual to make some decisions independently, based on his or her capacity, while decisions in certain more complex areas such as finances and healthcare are left to the guardian.

Supported Decision Making

So how does Supported Decision Making actually

work? “SDM is a process, rather than a legal category,” explains Ms. Phillips, “and the process should start early in the child’s life. Decision making is a skill, and if you don’t get experience with the skill, you don’t really know how to make a decision. Parents do this automatically with children who do not have a disability. They might ask: ‘Do you want to do your homework now or later?’ But often, children with disabilities have never been given choices.”

As the child nears the age of 18, and based on a psychiatric evaluation of his or her capacity to make decisions, parents should work with their child to set up a network of supports: people to whom he or she can turn for advice in making decisions in various areas of their lives. That may mean asking a family member for help in making certain personal choices, a financial advisor for help in money matters, a healthcare advocate for medical issues.

“It is very similar to the process that most adults use when making decisions. Just as we may ask a friend to help us when deciding where to live, or a family

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member when deciding on a job, or a professional when making financial or medical decisions, the individual with a disability can have the same opportunities, based on a designated group of supports,” notes Ms. Phillips.

Ms. Brenner, whose son has a developmental disability, has worked with him in setting up a SDM system. “My son has signed a Health Care Proxy, which allows him to say who can make medical decisions for him. He understands that he can make many decisions about his life, but he also understands that he can turn to me to sign medical releases.”

ARC Guardianship Training Workshops

In light of this shift toward more independence and more self-determination on the part of people with developmental disabilities, ARC of Rockland is in the process of revising the training workshops it provides on the subject of guardianship.

“Until now, we have focused on 17-A Guardianship, and the workshops have basically been about how to fill out the forms,” says Dinorah D’Auria, Managing Director of Clinical Services at ARC of Rockland. “But we have decided to expand the information provided and are in the midst of creating training sessions that cover all three forms of guardianship: 17-A, Article 81, and SDM.

“The emphasis will now be on SDM. On a quarterly basis, we will offer an SDM workshop first. Then, for the subset of people who feel that legal guardianship is still the only way to go, we will also have quarterly presentations on 17-A and Article 81 Guardianships.

“We can’t deny that there are people who are better off when under full guardianship,” says Ms. D’Auria. “But full guardianship is not necessarily the best for all people. Many can make their own decision in some cases and use the help and support of friends and family in other areas.”

“SDM is what we do every day,” says Ms. Phillips. “Why shouldn’t people with disabilities be offered the opportunity to do the same thing?”

For more information about ARC of Rockland’s Guardianship Workshops, please contact Danielle Loffredo, 845-267-2500, ext. 3054. ■



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The Quest to Prevent Alzheimer's Disease Down Syndrome Providing Clues

"I am enormously excited about writing off Alzheimer's as a problem by 2050," says William C. Mobley, MD, PhD, Chairman of the Department of Neurosciences at the University of California, San Diego School of Medicine and Chairman of the U. S. Scientific Advisory Committee of the Jerome Lejeune Foundation.

An aging population and the concurrent increase in dementia have made the need for a solution—be it treatment or prevention—of imminent importance. "If there are approximately 5 million people who have a diagnosis of Alzheimer's disease now, there will be 12 to 15 million by 2050. For every person with Alzheimer's, there are two and a half people taking care of them," says Dr. Mobley. "Those numbers will continue to rise and the number of dollars necessary to care for people with dementia could reach a trillion."

Dr. Mobley points out that the appearance of brain changes are predated by other changes in the brain. "We would have to go back 15 or 20 years earlier to figure out how and when these initial changes—these markers of future dementia—occur." It is the identification of these earlier signs which researchers expect will lead to the development of preventative measures.

"To identify the biomarkers, we can study familial Alzheimer's (families in which the condition is known to be inherited)—and of which there are potentially a few thousand subjects," says Dr. Mobley. "Or, we can ask in what other disorders the brain changes associated with Alzheimer's disease occur."

While researchers do not yet fully understand why this is so, they do know that by the age of 40,

plaques and tangles, the most prevalent brain changes characteristic of people with Alzheimer's, are present in all people with Down syndrome. "The average longevity of people with Down syndrome is 60 years. By the age of 55, roughly half will have dementia," says Dr. Mobley. "If they live to age 70, 80 percent will have Alzheimer's. In the United States alone, there are 120,000 people with Down syndrome ages 40 and over." This large number of people gives researchers the opportunity to think about what causes the disease, "to anticipate it," says Dr. Mobley. "What an amazing situation, not just for people with Down syndrome, but for everybody else."

Among studies currently underway are those involving families in which the disease is known to be inherited. "The genes inherited in these families powerfully define the eventual emergence of Alzheimer's disease, and biomarkers can be used to inform the pathological process well before the onset of dementia," explains Dr. Mobley. For people with Down syndrome, the pathological process appears to be very similar, but they do not inherit the disease. Rather, they carry an extra copy of chromosome 21 which causes the disease. The important question is how the extra chromosome does so."

Dr. Mobley enumerates several ways in which researchers are approaching the study of Alzheimer's. "One of the genes on chromosome 21 is the Amyloid Precursor Protein (APP). If a person has three copies of the gene, he or she will get Alzheimer's disease. If the person has two copies, he will not get Alzheimer's. We need to understand how the third copy of APP causes a problem. Studies are underway to find out what the third copy does and how to combat that third copy. There are two or three things we can do. We now know

that the full length APP and two of its products induce changes that resemble Alzheimer's. We can attempt to decrease the levels of those protein products, we can vaccinate against one or more of those products or, we can try to turn down the effect of the APP gene by preventing its expression," he explains.



“The average longevity of people with Down syndrome is 60 years. By the age of 55, roughly half will have dementia.”

—William Mobley, MD, PhD

cognitive measures and biochemical measures. We expect to see if the vaccine is safe and if there are early indications of efficacy. If so, we will move to Phase II to determine if the

people are maintaining cognitive status.”

Given existing insights, Down syndrome provides a nearly unique opportunity to prevent Alzheimer's disease. Rather than treating Alzheimer's, Dr. Mobley says that research aimed at preventing dementia could bear fruit. Building on studies in Down syndrome, he envisions a future in which, “Everybody will be screened for disease markers and treated with medicines that combat the pathological process before onset of dementia, and Alzheimer's disease will go away.”

Phase I of a clinical trial is currently underway in which adults with Down syndrome are being vaccinated against the peptide known as A-beta, the main component of plaques that accumulate in the brain and are a defining characteristic of Alzheimer's disease. Researchers at University of California, San Diego School of Medicine and the Alzheimer's disease Cooperative Study (ADCS), in collaboration with AC Immune, a biotechnology company based in Switzerland, are testing the safety and tolerability of an immunotherapy vaccine that targets Alzheimer's disease characteristics.

Extensive interviews with the subjects, brain scans and monitoring are designed to evaluate the safety of the vaccine. The study involves 24 adults with Down syndrome between the ages of 35 and 45. Subjects are being treated for 12 months, with a 12-month follow-up. “We characterize the participants utilizing clinical

Dr. Mobley notes that relatively speaking, “We are just in the early days of research and treatments. But we shouldn't be impatient. This special population of people with Down syndrome gives us an amazing insight into Alzheimer's disease. There have been hundreds of millions of dollars spent on understanding and treating Alzheimer's. Though we don't as yet have an effective treatment, these investments have brought important new insights that are helping us to understand the disorder in the general population as well as in Down syndrome. As the work progresses, it will bring us closer to effective treatments for all of those impacted. There is no way that we are not going to make enormous progress in the next five or ten years.”

The push to combat the oncoming epidemic of Alzheimer's disease requires funding. To that end, Dr. Mobley suggests that the public thank Congress for the increased budget recently approved for Alzheimer's disease research at the National Institutes of Health. He also hopes that the special benefits of studying Down syndrome will prompt the public to encourage their congressional representatives to join the Congressional Down Syndrome Caucus. “We want to ensure that some of the funding coming from the National Institutes of Health for Alzheimer's be used for studies relating to Down syndrome.”

Dr. Mobley is optimistic that by 2050 we will be able to say, “Alzheimer's is a disease we used to have to deal with.” ■

Revising Expectations

The average life span of people with Down syndrome has been increasing. But increased age often comes with increased health problems. For people with Down syndrome, Alzheimer's disease is a significant concern.

Although the symptoms of Alzheimer's disease are similar for all who have it, detecting the onset is more difficult in people with Down syndrome because they already have problems with memory and cognitive functioning," says Fred Wetzel. Dr. Wetzel holds a PhD in Public Health and is an Affiliated Trainer of the National Task Group on Intellectual Disabilities and Dementia Practices of the American Academy of Developmental Medicine and Dentistry (AADMD).

"We need to differentiate between issues that are caused by Alzheimer's and those caused by some other health issue that would be treated differently. That is why it is key to begin annual screenings for people with Down syndrome when they are in their 40s, so that a baseline of intellectual abilities and behaviors can be recorded and changes noted."

Early symptoms of Alzheimer's can include reduced interest in, or ability to, communicate, as well as changes in memory, behavior, sleep/wake patterns, mood, and in coordination and walking. Careful annual screening of these behaviors can be very helpful in early detection. (A more detailed screening list can be found on the AADMD website.)

"Screenings can be done by anyone who has known the individual for six months or longer," Dr. Wetzel explains. "It can also be helpful to take a video of the person over time, perhaps doing the same task, so that you can then evaluate if there is a change in motor ability or visual acuity. Depending upon the

results of the screening and video, it may be necessary to refer the individual to a professional for further psychological and physical evaluation. It is also recommended that the person be seen by a geriatric neurologist or general geriatrician if something turns up in the screenings or if you have any suspicion of dementia."

Although there are no effective, long lasting drugs to arrest the progress of Alzheimer's, there are many things that parents and caregivers can do to help. "Before the onset of Alzheimer's, the focus for people with developmental disabilities had been on habilitation—the learning of new skills. But after the onset of dementia, the focus shifts to helping them retain skills as long as possible," notes Dr. Wetzel. "This is a difficult adjustment for parents, because for the entire life of their child, the parents have focused on teaching them. Now they have to change their expectations, because the ability to learn is lost."

This means that parents and caregivers will have to modify activities to deal with the disease process. For instance, "Don't give multi-step directions because the individual won't remember all the steps. Instead, for example, first tell the individual to go to the closet. Then tell him or her to take out a shirt. Then suggest putting on the shirt.... Everything has to be done step-by-step," Dr. Wetzel explains.

Another important point to remember is to avoid getting into power struggles with a person who has dementia. "For example, the person may ask 'Where's my Mom?' when in fact the Mom is dead. Don't argue with him or her. Instead, use a validation approach. You might say, 'Mom is on vacation and it shouldn't be long until she is back.' Essentially, you are going into their world. They might say 'Someone stole my book,' when you know that isn't true. But rather than pointing out that it isn't true, just say, 'Yes, if that happened to



“Before the onset of Alzheimer’s, the focus for people with developmental disabilities had been on habilitation—the learning of new skills. But after the onset of dementia, the focus shifts to helping them retain skills as long as possible.”

—Fred Wetzel, PhD

me, I’d be upset too,’” says Dr. Wetzel.

The National Down Syndrome Society (NDSS) suggests that “traditional methods of offering incentives or rewards can become counterproductive,” because the individual will no longer be able to remember the incentive in the short term. So you can’t promise that if he or she behaves, the reward will be ice cream, because they won’t remember the promise.

According to the NDSS, non-verbal communication also becomes critical as dementia progresses. The individual will rely more heavily on emotional cues such as tone of voice, facial expressions and body language. Smiling and avoiding negative tones can be very helpful.

There are also some environmental modifications that may be made. For example, dementia affects vision, so people with Alzheimer’s need 30 percent more light. They tend to misinterpret shadows and

may perceive them as something threatening. “It’s like when you wake up in the middle of the night and see a coat hanging there and think at first that it’s a person,” explains Dr. Wetzel. This phenomenon is known as ‘Sundowning’, and people with dementia get more upset as night approaches because of the shadows. It is therefore helpful to keep a nightlight on in the room.

“They are also confused by changes in color, so use stable colors throughout. Don’t use black and white because they will see the black spot as a hole,” adds Dr. Wetzel.

The progression of Alzheimer’s disease can be difficult for both the patient and the caregiver. “It is hard to sit back and watch someone you knew with certain abilities and personality traits as those abilities and traits begin to disappear,” says Dr. Wetzel. “The best thing you can do is to try to be patient, and to continue to provide love and reassurance.” ■

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Is it Really Alzheimer's Disease?

Pinpointing the Diagnosis in People with Down Syndrome

“Many people with Down syndrome are prematurely given a diagnosis of dementia without considering all of the other possible diagnoses,” says geriatrician Dr. Julie A. Moran. “There is absolutely a risk of Alzheimer’s disease in adults with Down syndrome, but it’s a risk, not an inevitability. There are many conditions associated with growing older with Down syndrome that go undetected and untreated.”

Julie A. Moran, DO, is a Clinical Instructor of Medicine at Harvard Medical School and a consultant in developmental disabilities/geriatrics at Tewksbury Hospital, a state public health hospital in Massachusetts. Dr. Moran also runs the Aging and Developmental Disabilities Program, a consultation service with the Department of Developmental Services for the State of Massachusetts.

“Vision and hearing impairments, an under-functioning thyroid, sleep apnea, depression, osteoarthritis, pain and celiac disease can all present symptoms that can masquerade as dementia,” explains Dr. Moran. “Many physicians feel unprepared to diagnose conditions as they relate to adults with Down syndrome. This is especially true when tasked with determining whether dementia might be emerging.”

“Geriatrics is not a well sought-after field among medical students, yet the need is desperate,” remarks Dr. Moran. Within the field of geriatrics and in the broader field of adult medicine in general, most medical schools and training programs provide little to no training on topics related to adults with intellectual and developmental disabilities. They may be introduced to developmental

disabilities in the field of pediatrics and human development, but they are never told the remainder of the story—that the person with Down syndrome, for example, is going to live for six or seven decades.”

Time plays a significant role in finding the appropriate diagnosis and treatment. “When I see people in consultation, my visits are between 90 and 120 minutes long. A thorough understanding of the patient’s history is the essential foundation upon which decisions and recommendations can be made. A careful history that accounts for the individual’s baseline abilities is critical to understanding changes that are observed with age.”

As a consultant, Dr. Moran may see a patient only once—and then makes recommendations that can be followed by the primary care physician. “The key reason that most people with Down syndrome come to me is change. Someone has observed changes as a result of growing older. My job is to assess the change and identify any root causes. If I am seeing the patient at age 56 for the first time, I try to have collateral informants around the table—someone or several people who know the individual well—a mom or sister or the manager of a group home—a person or persons who have known the individual for at least a few years.” Dr. Moran counts on this narrative history, “so that I can have a virtual picture in my mind of where that person started in life. If I’m meeting them for the first time and I’m being told that they look different, I rely on a richly detailed baseline description to get a better understanding of the scope of change over time.”

Once she has ascertained an overview, Dr. Moran uses a variety of “simple, interactive tools” to assess the patient’s memory and cognitive abilities. The specific tools or tests are geared towards the individual. “We work with common tasks. I might have someone sign



“Many physicians feel unprepared to diagnose conditions as they relate to adults with Down syndrome. This is especially true when tasked with determining whether dementia might be emerging.” —Julie A. Moran, DO

his or her name, draw a circle or a square, write simple sentences, name common objects.” The testing is made flexible to scale up or down depending upon the person’s baseline abilities. “The interactive testing is a snapshot in time of what the person is capable of doing and then can be repeated in subsequent encounters as a template for comparison.”

In addition to maintaining accurate medical records, Dr. Moran encourages caregivers, including family members, guardians and professionals who work in community residences to make note of the abilities of people with Down syndrome on a regular basis. Many of the adults in their 50s or 60s whom I see, have lost pieces of their narrative history along the way. Caregivers come and go, family moves away or passes away, and they take with them the story of what that individual was capable of throughout their lifetime. If, at age 25, the person could read and write in full sentences, read music, cook elaborate meals, recite the alphabet, calculate simple math problems, memorize

specific dates, etc., it would be helpful if that was recorded somewhere.”


Keeping records of achievements at all stages of life provides physicians and caregivers with a baseline by which to better recognize change. “The very definition of dementia states that the memory impairment must represent a significant decline from previous level of functioning. In adults with Down syndrome, you can’t make assumptions about what constituted their previous level of functioning. You have to take the history. Each person is different.”

For adults with Down syndrome, the recommended age for an initial screening for dementia is at 40. “This makes a big assumption that there is someone with expertise in this field to help with screening.” Actual specialists with expertise in adults with intellectual and other developmental disabilities are few and far between, but there’s much that can be accomplished through close partnership with the primary care physician.

Dr. Moran is author of a book entitled *Aging and Down syndrome: A Health and Well Being Guidebook*,

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which is available online and by mail free of charge at NDSS.org. This guidebook outlines the common issues that adults with Down syndrome can encounter with growing older and can help empower caregivers to advocate to their primary care providers to consider other coexisting conditions.

Based upon her assessment, Dr. Moran might recommend a sleep study, a check of the thyroid or the need for a change in the dosage of a medication. Identifying adverse effects or overlapping effects of medications are also key considerations, particularly in older patients.

Adults with intellectual disability are now routinely reaching old age, and there is an ever-growing interest in the topic of dementia. When it concerns adults with Down syndrome, Dr. Moran states, “It is important that we include this in the national discussion. (The

National Alzheimer’s Project Act was signed into law by President Barack Obama in January, 2011, requiring the creation of a strategic plan to address the Alzheimer’s disease crisis.)

“The combined focus on geriatrics and Down syndrome is a fantastic field,” says Dr. Moran. “There is never a dull moment, and this is an area where we can do a tremendous amount of good.” ■



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