



DSACK

beautiful capable loved

MAY-JUNE
2010
VOLUME IV
NUMBER III

DSACK Celebrates People!

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DSACK

DSACK celebrated our 3rd annual Appreciation Reception on April 18th

This is a day set aside to recognize community members that have helped DSACK throughout the year.

This year we recognized four board members whose terms have expired. Dixie Miller, Belva Collins, Malkanthie McCormick, and Brooke Reed have all been huge assets to our Board of Directors. They have given generously of their time and resources to help DSACK grow and meet the needs of our families. Thank you, Ladies! Words just aren't enough to tell you how very much you are loved and appreciated.

This was the first year we recognized an Employer of the Year. Jeremy Thompson nominated his employer, Movie Tavern. Jeremy loves his job and Movie Tavern has gone above and beyond to make this a positive experience for him and for their business.. Thank you, Jeremy, for sending in your nomination. Many of our young adults were present and proud to tell us of their work experience. We had several local businesses represented such as Kennedy Bookstore, Growing Together Preschool and McDonalds.

DSACK thanks everyone who worked hard to make this event a success. Special thanks to AIM member, Megan McCormick, who provided the beautiful piano music during our reception. Megan, you are a gifted musician!

So much of what DSACK has accomplished can be attributed to a community member who has looked beyond his/her own needs and busy schedules to take the time to give back. This is also true of therapists, educators, and so many others who diligently work with our loved ones with Down syndrome and our families to ensure a brighter future for all of us. We hope you make plans next year to join our Appreciation Reception and invite those that have helped you along your journey.



This year, Michael is going to enter 3 watercolor paintings of mares and foals in the AAEA Open Juried Art Exhibition in the fall. It is going to be at an art Gallery in Georgetown, 5 miles from the Kentucky Horse Park. He is currently working on paintings for Lane's End Farm, Darley's Jonabell Farm, and Blood-Horse Publications. He also supplied several race paintings for the Down Syndrome Association of West Michigan Kentucky Derby Party fundraiser at the local racetrack in Grand Rapids, MI. You can see some of them on the Horse Paintings page at www.artistmichaeljohnson.com.

In October Michael did a trunk show with professional artists from Chicago. They were blown away by his paintings! They had never seen watercolors like that before and couldn't believe they were watercolors! The local art gallery is going to give him an exhibit.

It is Michael's dream to have a painting at the AAEA exhibit this year. He is working hard towards his goal. Art collectors and gallery owners go to the exhibit. Maybe a Kentucky gallery will discover him!

Learn more about this amazing artist and view his paintings on his website www.artistmichaeljohnson.com. He is truly an inspiration to us all!

Who Are We?

BOARD OFFICERS

Traci Brewer, *Parent*
Courtney Elbert, *Parent*
Michelle Gilliam, *Parent*
Regina Schmutte, *Parent*
Eileen Miot, *Parent*

TREASURER

Lee Ann Mullis, *Parent & Consignment
Inventory Analyst/Accountant*

BOARD DIRECTORS

Belva Collins, *Ed.D. UK, Professor of Special Education*
Harold Kleinert, *Ed.D., Executive Director of HDI*
Samantha Matthews, *Special Education Teacher*
Brooke Reed, *M.S. UK School Psychology Doctoral Student*
Susan Hart Bell, *M.S., Ph.D., Parent & Professor of Psychology
& Coordinator of Child Development, Georgetown College*
Meada Hall, *M.S., Ed.D. Principle Investigator & Project Director
for Community Based Work Transition Programs, UK*
Matt Moore, *Director of Special Education, Jessamine County
School District*

ADVISORY COUNCIL

Caroline Boeh Baesler, *Parent & Attorney*
Karen Roof Boudreaux, *Parent*
Becky Lesche, *Parent & Educator*
Dr. James Riley, *Pediatrician*
Malkanthie McCormick, *Parent & MD
Internal Medicine Physician*

DSACK Bylaws and financials are open for review, and the Board of Director Meetings are open to our community. Agenda items are determined well in advance.

The DSACK Newsletter is published bimonthly by the Down Syndrome Association of Central Kentucky, P.O. Box 910516, Lexington, KY 40591-0516.

BUDDY WALK



Just Ask

Are there businesses that you frequent?

Do you know a business that would like to sponsor this years Buddy Walk?

Contact Regina Schmutte at remicale2@aol.com or 859-983-3754 for our Sponsorship packets.

Do you know someone that would like to donate an item to 2010 Buddy Walk?

Contact Amanda Jones at Amanda.Jones@nationalcity.com

Our Buddy Walk....

Our 2010 Buddy Walk registration web site is up and running!! Register your team! The first 3 families to sign up their team will receive a ticket for two to The Legends Ball Park! Go to www.buddywalk.kintera.org/dsack to start your team now!

Fun Facts about our upcoming Buddy Walk!

We are pleased to announce the Buddy Walk's 2010 Presenting Sponsor:



THE BANK OF LEXINGTON!

Thank you to the Bank of Lexington for continuing to support our organization. We appreciate your dedication!

WTVQ will be our media sponsor again this year!

The 2010 Buddy Walk T-shirt will be Yellow this year!

A **record** number of committee members/chairs have volunteered to assist with this year's Buddy Walk!



Join a Buddy Walk Committee

Marketing Committee

Chair: Geneva Harris, parent
Committee members:
Karen Hunter, parent
Elizabeth Miller, sibling



Volunteer Committee

Needs: Chair and 2-4 committee members

Auction and Raffle Committee

Chair: Amanda Jones, friend of DSACK
Committee members:
Marina Beckett, parent
Carol Coleman, parent
Needs: 4-6 committee members



Catering Committee

Chair: Karen Andreassen, parent
Committee Members:
Brian Calvert, friend of DSACK
Catherine Clements, friend of DSACK
Donna Robertson, friend of DSACK
Vikki Healy, parent

Sponsorship Committee

Needs: Chair and 2 committee members
Committee member: Allison Kerschbaum, friend of DSACK

Exhibitor Committee

Chair: Nicole Maher, parent
Pete Healy, parent



Registration Committee

Chair: Susan Bell, parent
Committee members:
Deb Berry, parent
Julia Fox Ruzzene, parent

Entertainment Committee

Chair Tracey Durham-Beall, friend of DSACK
Committee member:
Tammy Carter, parent

Need Buddy Walk 2010 Members!

We are still actively seeking Committee members and chairs for our 2010 Buddy Walk. Do you know someone that may be interested, a group or a friend? Do you want to volunteer? Contact Regina Schmutte at 859-983-3754 or remicale2@aol.com

DSACK

NEWS

FROM THE BOARD

After serving DSACK diligently for many years, Dr. Malkanthie McCormick has decided to step off the Board due to increased professional responsibilities and to be available for her daughter Megan's current interests and academic career. I know we all count Malkanthie as a personal friend. She has been such a mentor for those of us with younger children, and her wisdom and advice are second to none! Thank you, Malkanthie, for your unfailing commitment in helping DSACK provide a bright future for our loved ones and families. You are very much loved! I know Malkanthie and Jim will continue to be involved with DSACK, and we can look forward to many years of friendship with them and their beautiful daughter, Megan.

I am happy to announce that Eileen Miot will be replacing Malkanthie as an Officer on our Board. Eileen is married to Herve and has two beautiful children, Sebastien who is 4, and Marie Claire who is 2 and was born with Down syndrome. She has been very involved with DSACK and has been the originator and leader of our Mom's Night Out monthly socials and our newly formed Prayer Circle. In addition, Eileen was very instrumental in our Buddy Walk Silent Auction and secured many donations and gifts for that new venture last year. Her daughter's team came in a close second to the highest fundraiser for the Buddy Walk. Eileen also brings her experience as a social worker, which will prove to be a valuable asset in many areas. I know you all will join me in making her feel welcome. Thank you, Eileen for your careful consideration and willingness to serve DSACK.

Our Board continues to grow, not only in number but in diversity and expertise. We have been so blessed and owe a huge debt of gratitude to those that have served in the past and to those that will continue to serve in the future. I am honored and humbled to be a part of this wonderful Board.

Did you know that DSACK is run by a Board who volunteers their time and talent? DSACK needs you! DSACK has openings available on the Board! If you are interested in serving as a DSACK Board Officer, please contact info@dsack.org or call 859.494.709.

Respectfully- Traci Brewer
DSACK Chairperson

Looking For An Easy Way To Help Dsack That Won't Take Much Of Your Time?

We need someone to keep our Lending Library books and DVDs in a safe place, take online book orders and mail the titles to interested DSACK families. DSACK will provide the mailers and postage. There are about 45-50 books and a handful of DVDs. If needed, we could also furnish an inexpensive shelf. Historically, the Lending Library has not been used much, but we are hoping that with our new capability to order online this will change. The webpage now has a description of each title so that may also spark more interest. If you are interested, please call or email DSACK soon! 859-494-7809 or info@dsack.org.

Be Inspired!



I would like to thank you all so much for the support during Gabby's short life, her surgery, and her passing. I really appreciated the gift card and cookies at the hospital. I also appreciated the letters that were brought to us at the funeral home and the cards we received in the mail. I was so very ready to be a lifelong advocate for my precious daughter. I never dreamed God would call her home so soon. I miss her with everything I have, but I know her time on Earth was not without purpose. She taught me and SO MANY others so much about life, love, acceptance, and joy. I hope to continue being an advocate for all people with Down syndrome and share Gabby's story with anyone who will listen. Again, thank you so much for the support during this very difficult time. My husband and two other daughters were also very touched by your kindness.

I would like to share this video of Gabby with you.
<http://www.youtube.com/watch?v=XsaDytFFE7k>
Emily Merrick
www.caringbridge.org/visit/gabbysheart



The following is an excerpt from the beautiful blog of Florida mom Kelle Hampton. Her baby Nella, who has Down syndrome, is 3 months old. You can visit her blog at www.kellehampton.com

"Obviously, this sort of change in one's life causes months of reflection and, although life has moved on so perfectly and regularly for us, there are those mornings in the shower where I'm deep in thought, those drives along quiet streets where I contemplate it all, those nights where I lie awake and take it all in.

And the conclusion I come to is...*Thank you, Nella.*

You have stolen my heart with your almond eyes and your soul that twists me in two sometimes. Thank you for changing me. For opening my heart to learn more about the world and the beauty that's out there.

Thank you for teaching me to love--truly love--not only you but every blessed thing I've been given.

Thank you for challenging me--to accept fears and hardships and to use them to make me better.

Thank you for giving me time that night just weeks ago...for loving me through the pain...for waiting for me to come along on this journey with you. Thank you for holding my hand as I walk with you. I know there will be challenges, but I also know you'll always be my side and that in itself makes any pain seem to fade.

Thank you for setting us straight. A little sieve, you are, straining out the unimportant, the silly things in life that so often distract us from what really matters. You will forever be our filter and with you, what's left in the end is us...our family and our love.

Thank you for opening my eyes to a new kind of perfection--that which is good and beautiful and pure.

You bring nothing but joy and hope into our home, and I can't wait to see where you will take us. Our bunny. Our sweet Nella Wafer. Our Girl."

DSACK GROUPS

Advocates in Motion (AIM) Teen & Young Adult Group

In April, many of the group members attended the UK Cats Dance which was a blast! We got to meet UK athletes, eat, participate in a cake walk, play cornhole, and DANCE! This was the second year we attended the dance and it was so much fun! The next AIM event will be a family cookout at Megan McCormick's house in June. Siblings and parents are invited to attend! We will eat, socialize together, and discuss future directions for the AIM group. Please call or email Brooke Reed for more information (brooke.reed@uky.edu or 502-554-3190).



Elementary Group

The next elementary group meeting will be held on May 22, 2010 from 1-3 at Red Robin in Brannon Crossing! Kids eat Free and activities will be provided for them during the meeting session. This meeting will focus on parents discussing where we want to see the group go, activities and places they would like to attend, and specific topics that will be beneficial for their child at this time. The elementary aged parent packets will be given out at this time. Parents please come with ideas of where and what you would like to learn about and don't forget to RSVP to Sam at 270-256-2002 or email at Samantha.matthews@jessamine.kyschools.us

0-5 Parent Group & Playgroup

June 12th, July 10th, August 7th - no 0-5 meetings during the summer! Enjoy the special summer events that DSACK has planned! Check the online calendar periodically for updates at www.dsack.org.

All meetings are on the 2nd Saturday of the month, 10-12, at Faith Lutheran Church, 1000 Tates Creek Rd in Lexington. This group is for families who have a child with Down syndrome between the ages of 0-5 years old. Siblings and grandparents are welcome. Childcare is provided. Contact Michelle @ 859-223-4207 or newparentgroup@dsack.org for more information.

Hi! My name is Anna Brannen. I am a parishioner of St. Elizabeth Ann Seton and a committee member of a new committee called SPICE (Special People In Catholic Education). To promote our committee and provide a fun inclusive camp opportunity we are putting on a drama camp in July. The information is below!

Get ready for a great summer experience where children of all abilities are encouraged and supported to shine!

Campers will be a part of putting on a play and making new friends. The camp ends with an exciting performance of *The Hungry Caterpillar* on Friday, the 16th at 10:30am for your family and friends. *Awards for each camper are included!

DSACK Prayer Circle Group,

Thank you for being patient as I, with God's help, organized the DSACK Prayer Circle. I am not blessed with hearing God audibly. He does nudge me to seek out assistance when I need it. He lead me to Rev. Bell.

I am very pleased to announce that Rev. Jeff Bell-Senior Minister of First Christian Church of Paris, KY will be the Steward of the DSACK Prayer Circle. Rev. Bell is father of Chad Bell, a member of DSACK's Teen & Young Adults Group (AIM). We are uniquely blessed to have Rev. Bell assist us.

Rev. Bell and I developed the following guideline:

Person requesting prayer can:

- send prayer request to the Church's (Secretary: Dianne Stubblefield) email fccparis@bellsouth.net
- call the Church leave prayer request message with secretary Dianne Stubblefield
- call Rev. Bell's cell directly at 859-707-7886

So as to have prayer request accurate, the person/parent requesting the prayer needs to request it themselves.

Prayer request should include:

- what you want us to pray for
- indicate whether you want request to be shared with the First Christian Church's Prayer Circle or just DSACK's Prayer Circle Group

Once request has been made:

- Rev. Bell or his staff will forward your email prayer request to those DSACK members who are a part of the DSACK Prayer Circle. Please do not share prayer request with others.
- If you requested, Rev. Bell will also forward request to the First Christian Church's Prayer Circle

Be assured that:

- Your prayer request will be prayed for by the Circle(s) * Due to the sensitive nature of prayer requests let us all adhere to confidentiality

I am very excited to get started...I do so believe in the power of prayer.

I would love it if someone could create a prayer...for our kiddos, parents, siblings & extended family, educators, Dr's, organization, etc...that we could say daily when we don't have someone specific to pray for! Please submit to me if you come up with anything.

Please contact me if you have any questions. erwky@yahoo.com or 859-340-2771.

Thank you for participation.

Blessings, Eileen Miot

LOCAL NEWS TO USE

Tuesday, July 13th -Friday, July 16th

9:00am - 12:00p.m

Seton Catholic School

Main Instructor: Anna Brannen

Tuition: \$25/camper

(scholarships are available)

To register or more information, contact Anna:

E-mail: annaharkenbrannen@gmail.com

Phone: 1 402-203-5603

D S A C K

Transition From High School To Work (Part II)

Supported Employment for Adults (Part Two)

* This article is the second in a 2 part series focusing on transitioning into work. This article was written by Tammy Smallwood and is based on her interview with Milton Tyree, the Project Director of the Kentucky Supported Employment Training Project.

If you missed the first article, be sure to read Transition from High School to Work (Part One) based on an interview with Dr. Meada Hall who is the Program Director of the Community Based Work Transition Program. You can read the article in its entirety online in the "newsletter archive" at www.dsack.org!

Having a job is more than just a means to pay personal financial obligations. Having a job influences a person's sense of personal identity, and creates a sense of belonging to a place in the world where one fits in and feels welcomed. Moreover, having a job represents a way of expressing the innate human need to contribute to one's community, and doing something that matters to the individual.

However, the significance of employment for people with disabilities has been unrecognized, ignored, or curtailed for far too long. This is not always the fault of the general population, but the people with disabilities and their support system as well. Some employers are not aware of the capabilities of people with disabilities. Often, people with disabilities may also be unaware of employment opportunities due to the fear of losing their federal money, or that they are not competent enough to work. Of course, this is not always true for either case.

Throughout the state, there are over 80 agency providers affiliated with the **Office of Vocational Rehabilitation (OVR)**, which is available to assist people with disabilities in job search assistance. But, what does OVR do and how are we made aware of their services?

Milton Tyree is the Project Director of the **Kentucky Supported Employment Training Project** and his project consists of training qualified vendor agencies in supported employment, and what it entails. In 1985, Kentucky was one of ten states that were selected to pilot a federally funded "supported employment training project". In 1988, the current project began; it has expanded to over 80 supported employment vendors available to the target community. The success of this project is due because Supported Employment has shown, time and again, that *people with significant disabilities can be successful in good jobs*. Often times, it just takes the right job in order for someone to be successful.

How does Supported Employment work? Supported employment is designed to promote personalized employment opportunities for people with disabilities. Support is offered to help individuals discover personal interests and contributions, find or negotiate a job that fits things they like to do and do well, become recognized as a valued employee, and seek possible job advancements.

The Kentucky Office of Vocational Rehabilitation (OVR) pays vendors for the service of Supported Employment. In order to receive payment from OVR for this service, an agency must become a vendor of OVR. Vendors of Supported Employment with OVR must attend the Supported Employment Core Training Series offered through Milton Tyree's Kentucky Supported Employment Training Project at the University of Kentucky Human Development Institute.

During this training, the vendors learn how to conduct *person-center job selections (PCJS)* in which the vendor learns a courteous way to get to know people who are seeking jobs and a way to break past preconceived ideas about what a person can and cannot do based on previous thoughts of the limited abilities of people with disabilities. Without really knowing and understanding someone, it is difficult to find a suitable job where he/she can be successful and motivated to perform well in his/her place of employment. This is why PCJS is so significant to supported employment.

After this initial step, then the vendor finds new and positive job opportunities with the person they are assisting, and begins an agenda for planning job maturity and job compromise with a potential employer.

Once the vendor is qualified to conduct support employment services, they will begin to receive referrals from the OVR for people with disabilities that are eligible for services and employment. Once the individual with disability is referred to a vendor and the vendor conducts PCJS with their assigned client they will begin creating a person-centered job plan. Finally, then the job development begins.

The jobs for which these vendors are looking must be in conjunction with the employment goals made with their client during the PCJS and in creating the Person Centered Employment Plan. Job Development activities include job shadowing and touring a prospective company with their client. Talking to these prospective employers about their client/potential employee and practicing interviewing skills. They assist in developing a resume and preparing the individual for the application process and the upcoming interview. The vendor gets to know the potential company to make sure it's a good match between the potential employer and employee. If it is a good match then they will secure employment for their client.

Once a client begins a job then the vendor begins looking for long term support for their client. During this time they will ensure that the client/employee is learning the job, is identifying and connecting with natural supports at the workplace, and is becoming comfortable in the workplace. The long term support does not mean that the vendors are required to remain with the supported employee at the job site but they are available if they are needed for extra support or assistance with job changes/advancements. Therefore, they are expected to check in with the supported employee and employer on a regular basis. Once a client is settled into his/her new job, the vendor will search for other long term supports. These supports are paid via different sources, such as using the SCL waiver, depending upon the individual and the agency.

For a list of vendors in Kentucky please visit this website and mention the possibility of future employment to your counselor at the OVR office. http://www.kyapse.org/se_providers.htm

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REACHING OUT TO SUPPORT RESEARCH

Down Syndrome, Aging & Alzheimer's Disease Study

This comes from our very own DSACK Board Member, Dr. Harold Kleinert. Let's reach out to support local research opportunities that are funded by the National Institute of Health.

Please find [below] information about the University of Kentucky's Down syndrome and Alzheimer's Research Project. The Louisville and Cincinnati Down syndrome Associations are both participating in this research, and it is an important opportunity for older individuals with Down syndrome and their families. I am on the Advisory Board of this project here at UK, and I believe it could lead to important findings to help adults with Down syndrome, especially as they age.

Thanks! Harold

Purpose of the Study

This research seeks to understand how Down syndrome and Alzheimer's disease may affect a person's memory and thinking as they get older.

The goals of this longitudinal project are:

- to follow neurological, learning and memory changes in adults with Down syndrome as they age;
- to examine brain changes using MRI and;
- to measure blood biomarkers.

In combination, the study hopes to identify early markers of the development of Alzheimer's disease in Down syndrome.

Who Can Join?

- Persons with Down syndrome age 35 and older with or without signs of Alzheimer's disease are eligible.
- Volunteers must be interested in participating in a five-year research study.
- You, a family member or caregiver will need to answer questions about your health.

For more information contact:

Roberta Davis
(859) 257-1412 ext. 479 or
rdavi3@email.uky.edu

Why Should I Join?

Volunteers are being invited to take part in a research study involving 50 people with Down syndrome, which is being done as part of a study that is funded by the National Institutes of Health. You can help us to better understand how memory and thinking change in persons with Down syndrome as they get older and why they are at a higher risk for Alzheimer's disease. There will be no direct benefits to you from the research tests in this study. But, you may benefit from the medical examinations, blood tests and brain scans and they may show a disease or illness that needs further treatment. If we find a disease or illness, the study doctor will tell your guardian and your primary care doctor within 72 hours so that you can be treated.

What will happen if I take part in the study?

- You will be scheduled for memory and thinking tests and a physical examination.
- This is about a three-hour visit, at the University of Kentucky.
- You will be asked to take tests that measure thinking skills and memory every 6 months.
- You will be asked to give a blood sample and have a brain MRI scan each year.

How Down Syndrome Stops Cancer

Customized Down syndrome stem cells reveal a way to starve tumors.

By Jocelyn Rice

<http://www.technologyreview.com/biomedicine/22681/page1/>

For decades scientists have known that people with Down syndrome, who have an extra copy of chromosome 21, get certain types of cancer at dramatically lower rates than normal. Now, partly by using stem cells derived from the skin of an individual with Down syndrome, researchers at Children's Hospital Boston have pinpointed the gene that appears to underlie the cancer-protective effect.

The researchers say the results of their study, which were published today in Nature, may point to a promising new target for future cancer treatments.

The late Judah Folkman, a cancer researcher renowned for pioneering the notion that blocking angiogenesis--the growth of new blood vessels--can prevent tumors from thriving, hypothesized that the lower cancer rates associated with Down syndrome might be traced to anti-angiogenesis genes on the 21st chromosome. So Sandra Ryeom, a member of the Folkman Laboratory in the Vascular Biology Program at Children's Hospital, zeroed in on a region on chromosome 21 known to encode a regulator of blood vessel growth called DSCR1.

In chromosomally normal mice, the standard two copies of the *Dscr1* gene produce just enough protein to help reign in normal blood-vessel growth, but not enough to stem the angiogenesis overload triggered by a developing tumor. But in mice with an artificial version of Down syndrome (and thus a third copy of the *Dscr1* gene), Ryeom found that the surplus of DSCR1 protein kept abnormal angiogenesis--and the resulting tumor proliferation--in check.

While Ryeom and her colleagues suspect that DSCR1 works in concert with a handful of other chromosome 21 genes, they confirmed that the protein plays a central role in tumor suppression. A third copy of the *Dscr1* gene alone was enough to stifle cancer formation in otherwise normal mice, though not to the same degree as in the Down syndrome mice.

To confirm that the gene is relevant in human cancers, Ryeom and her colleagues created a custom line of stem cells from skin cells taken from an individual with Down

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syndrome. Using a relatively new technique called induced pluripotent stem (iPS) cell reprogramming, researchers can express specific genes in differentiated adult cells and revert them to an earlier developmental state, where they are capable of giving rise to many different cell types.

Human iPS cells offer a convenient means to study cancer growth. Injected into mice with compromised immune systems, they generate chaotic but benign tumors composed of many kinds of tissue. When the researchers injected iPS cells derived from a chromosomally normal individual, the resulting tumors spawned elaborate networks of blood vessels to feed themselves. But when Ryeom's team injected iPS cells derived from a Down syndrome patient, the tumors formed hardly any blood vessels at all.

Now that Ryeom and her colleagues have shown the importance of the DSCR1 pathway in blocking tumors, the researchers are testing it as a potential target for cancer drugs. By chopping the protein into tiny pieces, they have identified the smallest chunk required to interfere with abnormal blood-vessel growth. Ryeom envisions using that chunk not just as a treatment for cancer, but also perhaps as a prophylactic. "If we could take this as sort of a preventative, vitamin-like therapy," she speculates, "would it block all of us from having tumor cells grow into these huge, lethal masses?"

Debabrata Mukhopadhyay, a professor of biochemistry and molecular biology at the Mayo Clinic Cancer Center in Rochester, MN, advises caution. He says that because the role of DSCR1 in normal development isn't yet well understood, toying with its biological pathway might have unintended consequences. He is optimistic, though, that the new study will help researchers begin to decipher that mechanism.

"If there is any distinct difference between DSCR1's effect on pathological versus physiological angiogenesis, that needs to be resolved," says Mukhopadhyay. "But this is a very important way of looking for anti-angiogenic therapy."

Down Syndrome Patients Could Unlock Mysteries of Aging

by Liz Szabo, USA Today

http://www.usatoday.com/news/health/2010-03-22-down22_CV_N.htm

In 1950, when Marybeth Solinski was born, a diagnosis of Down syndrome was practically a death sentence. Children with the condition often died before their 10th birthday. Yet Solinski, at 59, has outlived her parents. She has even joined AARP. Her longevity illustrates the dramatic progress for people with Down syndrome. Thanks to better medical care, the average life expectancy for a child with Down syndrome is now 60 years, according to the National Down Syndrome Society, which estimates that about 400,000

people are living with the condition in the USA.

As they live longer, adults with Down syndrome — who have an extra copy of chromosome 21 — are teaching scientists about the genetic roots of aging, says Ira Lott, head of pediatric neurology at the University of California-Irvine School of Medicine.

Scientists today are searching this chromosome, which contains only about 200 of the body's roughly 20,000 genes, to learn why people with Down syndrome suffer disproportionately from some health problems, such as Alzheimer's disease, but are spared many others, such as heart attacks, strokes and certain types of cancer.

By studying adults with Down syndrome, researchers hope to find new ways to combat diseases of aging in the larger population as well, Lott says.

"It's an interesting detective story," says Lott, head of the science advisory board of the National Down Syndrome Society. "People with Down syndrome are unique when it comes to many aspects of aging."

Aging troubles start early

People with Down syndrome tend to age prematurely as they develop conditions such as menopause, brittle bones, arthritis, hearing loss, wrinkles and sagging skin about two decades earlier than usual, says Brian Chicoine, medical director of the adult Down syndrome center at Advocate Lutheran General Hospital in Park Ridge, Ill., the leading center of its kind.

"People say they seem to age overnight," says Dennis McGuire, director of psychosocial services at the same center. "They suddenly develop wrinkles and gray hair."

Solinski, for example, wears a brace on one leg and hearing aids in both ears, and she has had two corneal transplants. "She's more like a 79-year-old than a 59-year-old," says her sister, Lee Cornell of Illinois.

Yet researchers suspect that this unique genetic profile also protects people with Down syndrome from many common ailments. A growing number of researchers are asking:

- What protects their hearts?

Half of babies with Down syndrome are born with correctable heart defects, and most adults with Down syndrome are overweight with high cholesterol. Despite these risks, however, people with Down syndrome virtually never develop high blood pressure, heart attacks or hardening of the arteries, Lott says. Doctors are still trying to learn why.

- Why don't they get cancer?

Doctors once believed that people with Down syndrome didn't live long enough to develop cancer, says Sandra Ryeom, a researcher at University of Pennsylvania School of Medicine in Philadelphia

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Yet, with the exception of a rare pediatric leukemia, even elderly adults with Down syndrome rarely develop solid tumors, such as those of the breast or lung.

Last May, Ryeom and her colleagues found genes on the 21st chromosome that inhibit the growth of blood vessels necessary for tumor growth. Getting an extra copy of these genes, and possibly others, may help the body keep cancers in check by depriving them of blood, she says.

Researchers already are trying to develop anti-cancer treatments based on genes found on chromosome 21, says Roger Reeves of Johns Hopkins University School of Medicine.

•What protects their eyes?

Although people with Down syndrome are at higher risk for cataracts, they rarely develop a form of blindness called macular degeneration, caused by an overgrowth of blood vessels in the retina, Ryeom says. Doctors suspect that the same genes that restrict blood vessel growth in tumors may also prevent abnormal blood vessel growth in the eye.

A link to Alzheimer's?

•Why do Down syndrome patients develop early Alzheimer's disease?

Adults with Down syndrome appear to develop the brain plaques and tangles characteristic of Alzheimer's disease very early in life — even as young as 3 or 4 years old. For decades, however, their brains also appear to repair and compensate for the damage, says scientist Elizabeth Head of the University of Kentucky's Sanders-Brown Center on Aging.

"Their brains may be clearing the plaques," says Head, who is now recruiting Down syndrome patients for a study on biomarkers of Alzheimer's. "As they get older, this protective process slows down."

By age 40 to 45, virtually everyone with Down syndrome has these plaques and tangles, although only 12% have dementia, Lott says. By age 65, up to 75% of people with Down syndrome have dementia.

Significantly, doctors have found a gene that increases the risk of Alzheimer's, called APP, on the 21st chromosome, Lott says. The gene, called amyloid precursor protein, is involved in the creation of the brain plaques seen in Alzheimer's patients. People who inherit mutated copies of these genes may develop Alzheimer's disease decades earlier than usual, says William Mobley, a neuroscience professor at the University of California-San Diego.

Yet not all people with Down syndrome succumb. One of Chicoine's patients lived to 83 without dementia.

Solinski, of Chicago, loves learning so much that she takes flash cards on vacation. She pores over children's encyclopedias and Nancy Drew novels. She is learning to cook, she says, to follow in the footsteps of her mother, who died in August at 92. And, she says, "I want to be a great reader like my father."

And Brooklyn resident Edward Barsky is still healthy and independent at 73, living in a group home and navigating public transportation on his own, says his sister, Vicki Ploscowe.

"He's still going strong," says Ploscowe, of Manhattan.

If researchers could learn what protects certain people, they might be able to develop a therapy to prevent Alzheimer's — both in those with and those without Down syndrome, Head says.

'No other population' like this

People with Down syndrome present doctors with a rare opportunity to watch the disease progress, Lott says.

"There's no other population where you can really study this," Lott says. Although some people without Down syndrome carry a gene that increases their risk of early dementia, "you don't know who in the general population is going to come down with sporadic Alzheimer's. With Down syndrome, you know that virtually 100% of them will have plaques."

For example, doctors don't yet know exactly how an extra copy of chromosome 21 causes or prevents disease, Lott says. It's possible that getting a 50% larger "dose" of a gene affects the body's susceptibility to a disease, he says. Or, it's possible that the extra genetic material simply makes the entire genome more unstable.

Reeves says he's grateful to the Down syndrome community for teaching scientists so much.

"If it weren't for people with Down syndrome having fewer tumors," Reeves says, "we never would have thought to look for anything like this."

MAKING CONNECTIONS

Graduate Student Spotlight

DSACK says goodbye and thank-you to practicum students Rebecca Smith and Tammy Smallwood, both working on their Master of Social Work at University of Kentucky. Rebecca was involved in the Buddy Walk, researching and updating our database, and planning and leading several group activities



which included the 0-5, elementary and sibling groups. Tammy has been instrumental in assisting with several administrative duties, tutoring, organizing an elementary and AIM community service project and manning a DSACK booth at the recent Fayette County Disability Expo. We appreciate their invaluable hard work, creative ideas and insight and wish them all the best!

DSACK

WONDERFUL WEBSITES

Here are 2 blogs for you to check out. The first one has become a personal favorite of several DSACK Board Officers!

<http://www.kellehampton.com/p/about.html>

Enjoying the Small Things began in 2007, shortly after my first daughter Lainey was born, as a way to combine my writing and photography hobbies. It since has evolved to much more, providing not only an outlet for creativity (which, without, I'd go nuts), but a home for the gratitude I feel for all of my inspirations, most importantly, the moments we share as a family. Van Gogh used paints to portray what inspired him... Me? I like photos and words. I invest in this blog not only because I love the art of weaving words and images together to tell a story, but because, in doing so, I find myself looking more deeply for the beauty in life and consequently finding it in more places. This January, we welcomed our second girl, Nella Cordelia, and were stunned to learn, upon her delivery, that she had Down syndrome. My world was rocked to the core, and I was sure life as I knew it was over. How wrong I was. Between the outpouring of love and support we received, some hardcore life analysis and therapeutic insights I made on this blog through it all, I have arrived at the very beautiful place of Life is hard. But it's also amazing, and I will rock the hell out of it. *I will not die an un-lived life. I will not live in fear of falling or catching fire. I choose to inhabit my days, to allow my living to open me, to make me less afraid, more accessible, to loosen my heart until it becomes a wing, a torch, a promise. I choose to risk my significance; to live so that which comes to me as seed goes to the next as blossom and that which comes to me as blossom, goes on as fruit.* -Dawna Markova

I live in Naples, Florida with my husband Brett, his two boys, Austyn and Brandyn, and our girls Lainey and Nella. After three years of teaching 5th grade, I closed the doors of my classroom to explore other loves in life which include my photography business and writing, not to mention wading in a huge pool of other interests--many of which I pretend I'm good at. I love, in no particular order, family Sundays at Isle of Capri, baking with my girls, wearing really cute shoes, playing with make-up, pretending I can cook, drinking coffee with my friends, finding amazing golden light, planning birthday parties, and dreaming of the many places I'd like to take my family. I think there are millions of amazing people on this planet and I love knowing that inspiration is a two-way street. I hope to inspire and if I do, it is only because I am connected through a creative circuit to the constant flow of energy I draw from others who are far more amazing than me.

<http://communicationskillsforlife.wordpress.com/>

This comes from the national DS ListServe whose posting member says the following about it: "My daughter's wonderful speech therapist, Jennifer Bekins, has started a new blog! She is a speech language pathologist in Cincinnati, and has siblings with Down syndrome. I am so excited that she is going to be feeding this blog on a regular basis! She is very practical, down to earth and realistic when it comes to what is doable. I think you'll enjoy her as much as I do."

DONATIONS RECEIVED

In honor of Ava Gilliam by Alpha Master Chapter of Beta Sigma Phi, via her great-aunt Eugenia.

Volunteer Spotlight

DSACK awarded the Karen Boudreaux "Something Extra" Award to Samantha Matthews for her extraordinary service to the DSACK families. This award is given annually to an individual or business who goes above and beyond the call of duty, giving 110%. Sam came to DSACK a year ago asking to be involved, quickly started attending DSACK functions, began visiting with families in the hospital and even chaired the Buddy Walk sponsorship committee last year. She is on our Board of Directors and will be leading the elementary group starting this summer! Besides having a big heart, Sam is creative and very well qualified to help us. She is a special education teacher at Nicholasville Elementary School. Congratulations, Sam!



DSACK celebrated Brooke Reed's recent award from the United Way of the Bluegrass. She received the Central KY Volunteer Award for an Individual College Student for her extensive work with DSACK. As most of you know, Brooke founded and is the leader for the Teen & Young Adult Group (AIM), co-chaired the Buddy Walk volunteer committee last year and has served on DSACK's Board of Directors. The AIM group has had a huge impact on its members and their families, and she is very deserving of this award. Congratulations, Brooke!

Board Officer Spotlight

DSACK Board Officers, Courtney Elbert and Traci Brewer created and presented their first of hopefully many presentations entitled "Educating the Educators" On April 20th, they delivered this 1 hour presentation to future teachers at Midway College. The goals of the presentation were to: Establish a relationship; provide accurate information to future teachers; shape the attitudes of future teachers; and provide resources. They received extremely positive reviews on their evaluations. Thank you to Eileen Miot and Professor Kera Ackerman for arranging this presentation and helping to shape the future of how teachers educate our loved ones with Down syndrome.



DSACK Board Officers Courtney Elbert and Regina Schmutte and Parent and Advisory Council Member Karen Boudreaux gave a "Peer Presentation" to about 60 Boy Scouts and family members on March 22nd. This was a Pack meeting and the scouts ranged in age from 1st through 4th grade. The Presentation received great comments and reviews and we are hoping that ALL youth understand the DSACK vision that ALL people are beautiful, capable and loved! Thank you to Regina and Dr. Czar Crofcheck for coordinating this presentation for the Scouts.

DSACK Board Members Traci Brewer and Eileen Miot attended the Down Syndrome Affiliates in Action Conference in Kansas City recently. They plan to bring back many connections, resources, ideas, best practice information and more from this annual, national conference that connects Down syndrome organizations to each other.

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CALENDAR

Dsack's Annual Summer Picnic **Sunday, June 13th, 4:00 p.m.**

Veteran's Park Shelter #1, 650 Southpoint Drive in Lexington. Games and activities for all ages! DSACK will provide main dish, drinks and paper goods. Last names that begin with A-M please bring a side dish to share, N-Z please bring a dessert to share. Tables are limited, so you may want to bring a blanket or portable chairs for your family. In case of rain, call 859-494-7809 to check picnic status. Looking forward to a big crowd this year!

March with DSACK in Lexington's 4th of July Parade!

Would you like to join DSACK as we march in the 4th of July Parade? The parade will be on July 3rd at 2:00. If you are interested in joining, contact Regina at 859-983-3754 or remicale2@aol.com to find out more details.

DSACK to be Community Organization of the Night at Applebee's Park **Sunday, August 1st.**

It is a 2:05 game time, gates open at 1:00. DSACK will have a table set up, promoting our organization, as well as our Buddy Walk. One of our elementary age, or teen and young adult will have the opportunity to throw out one of the ceremonial first pitches. The winner will be determined by a drawing at the Summer Picnic, and there will be some free tickets available too! Contact Regina for more information 859-983-3754 or remicale2@aol.com

Advocates in Motion (AIM) Teen & Young Adult Group

Family cookout at Megan McCormick's house in late May or early June. Siblings and parents are invited to attend! We will eat, socialize together, and discuss future directions for the AIM group. Please call or email Brooke Reed for more information (brooke.reed@uky.edu or 502-554-3190).

Elementary Group

May 22, 2010 from 1-3 at Red Robin in Brannon Crossing! Kids eat Free and activities will be provided for them during the meeting session. Parents please come with ideas of where and what you would like to learn about and don't forget to RSVP to Sam at 270-256-2002 or email at Samantha.matthews@jessamine.kyschools.us

0-5 Parent Group & Playgroup

All meetings are on the **2nd Saturday of the month**, 10-12, at Faith Lutheran Church, 1000 Tates Creek Rd in Lexington. This group is for families who have a child with Down syndrome between the ages of 0-5 years old. Siblings and grandparents are welcome. Childcare is provided. Contact Michelle @ 859-223-4207 or newparentgroup@dsack.org for more information.

June 12th, July 10th, August 7th - no 0-5 meetings during the summer! Enjoy the special summer events that DSACK has planned! Check the online calendar periodically for updates at www.dsack.org.

DSACK BUDDY WALK 2010!

Saturday, October 2, 2010 @ The Thoroughbred Center
Registration at 9:30 & Walk at 11:00

SUBMISSIONS

Do you want to submit information for inclusion in the next DSACK newsletter?

Submission deadline is **Wednesday, June 16th** and can be sent to Courtney Elbert at celbert@roadrunner.com

Send DSACK pictures of your family member who has T21 to be included in the banner of the newsletter. Digital photos only. Photos should be of individual alone – head and shoulders preferred.

Do you... * Have an interest in placing an add in our newsletter?

* Want to receive the newsletter by email instead of through regular mail to save DSACK mailing costs?

* Know someone who might like to receive our newsletter?

If so, please contact Courtney Elbert at (859) 879-2182 or celbert@roadrunner.com

Let's get the word out about DSACK and our loved ones with Down syndrome who are beautiful, capable and loved!