



PACDS Newsletter

Parents Assistance Committee on Down Syndrome

Upcoming Events

Spring 2007

MARCH

3/14 Parent and Child Group

3/15 Resource Fair
(see pg 5)

3/24 AIM HIGH 15TH
Annual Conference
(see pg 5)

APRIL

4/18 Parent and Child Group

4/18 Transition Linkage Fair(see pg 5)

4/27 SPROUT Film Festival (see page 6)

MAY

5/16 Parent and Child Group

June

6/5 Golfing for Kids

6/13 Parent and Child Group

6/29- International Mosaic Down Syndrome Conference
(see pg 6)

August

8/3 NDSC National Conference (see pg 6)

8/5 PACD's Family Picnic (see pg 4)

September

9/17 23rd Annual MBIA Golf and Tennis Invitational (see pg 6)

Hello Spring!

It is that time of year again – IEP season. Many of you probably have been working overtime the last few months to prepare. If not, I have included in this newsletter some books that can help you get started. In addition, if you have not yet been on <http://www.wrightslaw.com/> - check it out! This site has a tremendous amount of information and resources listed on it. Just some quick IEP meeting tips: Meet with your child's teacher a few weeks before the annual IEP meeting to get an idea of what the school is thinking; prepare a list of questions and concerns before going to the annual IEP meeting so you don't forget anything while you are there; if someone uses a term within the meeting you are not familiar with please ask for clarification; bring an advocate or friend if you are feeling anxious; if the meeting is not moving forward and you are getting too frustrated to think ask them to reschedule and set a firm time and day before you leave; ask for a copy of the IEP before leaving; and be assertive but keep the lines of communication open both with your child's teachers and school administrators, it is important that you have an effective working relationship with the IEP team to meet your child's educational needs.

(PACDS does not promote or recommend any therapy, treatment, institution, etc., and does not espouse any particular political, educational or religious view. Inclusion of an item does not necessarily imply promotion or recommendation)

OUTDOOR FUN!

John Dillon Park Opened as the First Adirondack Recreational Area Designed Specifically for People with Disabilities and Their Caregivers

John Dillon Park opened July 06 as the first Adirondack recreational area designed specifically for people with disabilities and their caregivers. The park fulfills former International Paper chairman, John T. Dillon's vision for an Adirondack wilderness available to everyone. "The park is designed for people with disabilities to bring their friends, family and caregivers for an outdoor wilderness experience, through the installation of special adaptive facilities blended into a natural environment. The park demonstrates how well managed forests, manufacturing and forestry protection play a role in benefiting the Adirondacks. John Dillon Park is located in the heart of New York State in the Adirondacks on Grampas Lake. John Dillon Park, 2150 Tupper Road, Long Lake, NY 12847. If you are interested in more information or would like to make a reservation: Phone: October 1 to April 30: 518-327-6266 or send e-mail to registration@johndillonpark.org.

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CHILDREN WITH DOWN SYNDROME BREAKING NEW GROUND

Below I have listed a few articles that I have read over the last few months that discuss the growing wave of cognitively challenged students who are demanding, and gaining, a place on College campuses nationwide.

"University Assists Kids with Down Syndrome" (People Magazine article, October 2006)

The article talks about the University of Southern Maine and a young lady with Down syndrome who is enrolled at their school. The University has launched a new program to provide career and life skills for students with Down syndrome.

"Just a Normal Girl"

<http://www.ndss.org/> written by Leslie Kaufman

This article can be found on the www.ndss.org website. Ms. Apostolides has Down syndrome and was accepted at Becker College, a small liberal arts school in Massachusetts, a few years ago through regular admissions.

"Going to College: The Experiences of a Young Woman With Down Syndrome"

Journal: Mental Retardation Volume: 41 Issue: 5/written by Hamill, Lee B.

The article discusses a young woman with Down syndrome that audited two academic courses and participated in various nonacademic campus college activities. The research showed benefits to both the student's personal and professional development.

"Opening Doors Again: Postsecondary Education for People with Intellectual Disabilities" (Excerpt from article by Janet Gora, Executive Director, Down Syndrome Association of Greater Cincinnati; Reprinted with Permission)

I thought about naming this article, "The New Frontier," but was afraid it would conjure up thoughts about Mr. Spock and Captain Kirk. So instead, I'm going to call it "Opening Doors Again" to give a nod to the many years of hard work it took to include students with disabilities in the school systems. It's time to raise the bar again.

What's it about? Postsecondary Education (PSE)

PSE opportunities for adults with disabilities have grown phenomenally over the past five years. At that time of this article, there are 106 programs listed on thinkcollege.net which is the website funded by the U. S. Department of Education, National Institute on Disability and Rehabilitation Research, and the National Center for the Study of Postsecondary Educational Supports. Many people are surprised by the growing interest in PSE. People with intellectual disabilities going to college? How could that be? What does it look like? What type of student is successful? Well, I'll tell you what I have learned by reading, doing a little research and talking to people all over the country...

Websites of interest

Below please find an assortment of websites that may be helpful in your search for information.

www.ndss.org

National Down Syndrome Society

www.ndscenter.org

National Down Syndrome Congress

www.downsed.org

British website with extensive information

www.ds-health.com

Dr. Len Leshin, pediatrician and father of a child with DS. Articles and links to other websites. Of particular note: healthcare guidelines and growth charts.

www.metlife.com

Metdesk: financial planning for children with special needs.

www.woodbinehouse.com

Publishers featuring a special needs collection including many titles specific to Down Syndrome.

www.hwtears.com

Tips, materials and seminars focusing on pre-printing, printing and cursive writing.

www.talktoolstm.com

Sara Rosenfeld-Johnson site for seminars and speech tools (e.g. straw hierarchy, horns)

Opening Doors Again (Con't)

Why Do We Need PSE?

Nearly any type of PSE significantly improves the chances of individuals to secure meaningful employment. The data suggests that even one course leads to a job with more hours and better pay compared with the people who did not participate in PSE. The independence and confidence gained through the college experience is immeasurable. People who attend college may find that the fact that they attend college subtly changes the perceptions of peers, parents and community and they are more likely to be treated as equals in the adult world. The college experience also helps shape people's lifelong attitudes and values.

Interest is rising across the country. Because of IDEA laws, today's high school graduates have been included throughout their school life from pre-school to their senior year. They are expecting to go down the same paths as their brothers, sisters and high school friends'...college as a viable option. High schools are recognizing that helping kids attend college while maintaining a dual enrollment makes sense for them. It's a win-win situation. The schools don't have to come up with a new "program" or dedicate additional space to those students aged 18-22 and the students that are deferring graduation go to school with their peer group.

What Does PSE Look Like?

The 105 colleges listed on thinkcollege.net vary greatly in supports, classes, services and philosophy. Some colleges have set up substantially separate programs. Students with intellectual disabilities attend special classes that teach social, vocational, remedial academics, and/or other skills. Frequently, these colleges use education, rehabilitation or social workers majors to assist with skill development.

Some colleges have chosen to use the "inclusive individual support model" in which the student chooses classes to attend just like anyone else and receives individualized supports or "accommodations" to help them succeed. This philosophy maintains that removing students from mainstreamed college courses to their own special classes would be like returning to the pre-inclusive days before IDEA.

Some colleges allow for a mixture of both ideas. Students take one or two classes on campus and then return to their special classes for some subjects. Then there are students who are attending college without any program support at all!

For more information, check out these websites:

- www.thinkcollege.net
- www.ncset.org
- www.education.umd.edu/oco
- www.heath.gwu.edu
- www.transitioncoalition.org

Excerpt from article by Janet Gora, Executive Director, Down Syndrome Association of Greater Cincinnati; Reprinted with Permission



Annual Family Picnic

John Downing Park at Yorktown

August 5, 2007 Noon

RESOURCE/HUMOR

IEP RESOURCES

Deciphering the System: A Guide for Families of Young Children with Disabilities.

This book is for parents and families of young children with disabilities who are between birth and approximately five years of age and for older children. Topics include: the educational assessment process, handling educational planning meetings, due process hearings and a glossary to help parents sort out professional terms as well as an extensive resource list.

Individual Education Plan: Involved Effective Parents.

This book explains what occurs before, during, and after the development of an IEP, and provides a continuity process for transferring information from year to year. Includes forms for parents and educators. This book compliments the video, "The IEP: A Tool for Realizing Possibilities."

Better IEPs: How To Develop Legally Correct and Educationally Useful Programs.

This book is more of a guide to understanding and writing IEPs. It presents a three-step process that focuses on the individual student. This book is geared for both the educator and the parent in planning an appropriate education that reflects each child's specific needs.

HUMOR

Top Ten Signs You're Having Bad IEP Meeting By Colleen F. Tomko

We hope you enjoy the following from the www.mothersfromhell2.org humor page. Their disclaimer (& ours): "Disclaimer: What's funny to some is not funny to all. We cannot be in control of or responsible for your own personal tastes."

1. You over hear the staff talking about the Least "resisted" environment.
2. The staff is bumming because their label maker burned out.
3. They think "inclusion" is some type of venereal disease
4. The special ed coordinator says "Have we got a place for your kid?"
5. You find yourself explaining that... the regs say they can use IU's for related services, not I-O-U's.
6. They try to convince you that the attending speech therapist really is the janitor's identical twin.
7. Your child's student ID # is 666.
8. They give you complimentary white flags and tissues.
9. When you get to the meeting, the staff wants to know what you are doing there.
10. The IEP invitation lists "drive-thru" hours.

Source: Colleen F. Tomko. <http://www.mothersfromhell2.org/humor.htm>
(Another Resource to check out). Mothers From Hell 2, Box 62, Peru, Illinois



*Hear ye! Hear ye!
Get all the news as
fast as its out!
Send your email
address to Anne
Majsak to be
included in the
PACDS email chain
amajsak@optonline.
net*

PLANNING FOR THE FUTURE (RESOURCES CON'T)

It's never too early to start planning for your child's future. You might need to learn about living arrangements, wills, trusts, guardianship, and estate planning. You may also want to learn more about Medicaid, Medicare and Social Security benefits. Here are some web resources to help you begin your planning for the future studies.

In Special Needs: Planning for the Future at
<http://www.wrightslaw.com/info/future.plan.index.htm>

At this site you will find articles, books and videos, and free publications that will help in your special needs future-planning journey.

When Disability Aid Can't Provide for Toys & Haircuts, Special Needs Trust Helps

<http://www.altonweb.com/cs/downsyndrome/index.htm?page=feetrust.html>

Special Needs for School-Age Children: Planning Ahead When Your Child Has a Disability

http://www.bridges4kids.org/articles/7-06/onesource_future.html

Choosing the Ideal Trustee of Your Child's Special Needs Trust

http://www.eparent.com/lifeplanning/financial/financial04_04.htm

Special Needs: Planning for the Future

<http://www.wrightslaw.com/info/future.plan.index.htm>



Save the Date

Future events to mark on your calendar

March 15, 2007 – SPECIAL NEEDS RESOURCE FAIR

Sponsored by the Mount Pleasant Special Education PTA

Columbus Elementary School, 580 Columbus Avenue, Thornwood.

6:30- 9 pm. For information about this event, please call Sherril Bastardi 769-8965 or MaryJane Au 741-6491

March 25, 2007- AIM HIGH 15TH ANNUAL CONFERENCE

Beyond Our Wildest Dreams—15th Annual Conference, at Albany Marriot Hotel, Albany, NY. March 24, 9:00 a.m. to 4:00 p.m. Sponsored by the Down Syndrome Resource Ctr: 518-283-5316. or www.aim-high.org

April 18, 2007- TRANSITION LINKAGE FAIR

Information and networking for people with disabilities about transitioning into the adult world. High school students and recent graduates with disabilities, ages 12-25. Agencies will provide information on housing, employment, financial planning, and more. 6:30 - 8:30 p.m. White Plains High School Library, 550 North Street, White Plains, NY 10605, Free event - light supper will be served, Contact: Ellen Weinstein, 914-682-3296, ext. 114

Save the Date (Continued)

APRIL 27/28, 2007 –SPROUT FILM FESTIVAL AT NYU'S CANTOR FILM CENTER. The Film Festival aims to raise the profile of people with developmental disabilities and to showcase works of all genres. 36 East 8th Street, Manhattan-. www.gosproust.org/film

JUNE 5, 2007- GOLFING FOR KIDS

Annual golf outing benefiting Westchester Arc's. Children's School for Early Development. Contact: Fran Higgins, 914-428-8330, ext. 3028,

June 29, 2007- INTERNATIONAL MOSAIC DOWN SYNDROME ASSOCIATION

The International Mosaic Down Syndrome Association Is holding a research and awareness conference June 29 – July 1 in Richmond VA. It is open to and will be of interest to families with all forms of Down syndrome. More information at www.imdsa.com or 1-888-MDS-LINK.

August 3-5, 2007- THE 35th NDSC NATIONAL CONVENTION

NDSC's 35th Anniversary National Convention will be held in Kansas City. Hotel information is available. Remember, hotel rooms for the convention book go quickly, so don't delay!! <http://www.ndsccenter.org/news/convention.php>

TRANSITION/POSTSECONDARY PARENTS NETWORK

Transition/Postsecondary Parents Network, sponsored by Parent-to-Parent and the Hudson Valley Transition Coordination Site, is setting up a talk/email network for parents and professionals addressing transition issues. For information: 914-493-1027.

SEPTEMBER 17, 2007- 23rd Annual MBIA Golf and Tennis

Invitational

Benefiting Westchester Arc and Special Olympics-Hudson Valley.
Contact: Elyse Fowler, 914-428-8330, ext. 3027

IN SYMPATHY

We are saddened to have to inform you of the passing of Leah Levitz Fishbane, daughter of Barbara and Jack Levitz. Condolences can be sent to Mr. & Mrs. Jack Levitz, 208 Lafayette Avenue, Peekskill, NY 10566. The following is her obituary from the Journal News.

Leah Levitz Fishbane, age 32, of Teaneck, New Jersey, died suddenly on March 1, 2007 after a brief illness. Beloved wife of Eitan and mother of Aderet, she is survived by her parents, Jack and Barbara Levitz and her brother, Mitchell Levitz of Cortlandt Manor, New York and her sister and brother-in-law, Stephanie and Rabbi David Englander and family from Boca Raton, Florida and grandmother, Lee Gibbs of Monsey, New York. Her family is joined in mourning by in-laws Michael and Mona Fishbane of Highland Park, Illinois; Elisha and Tzippy Russ-Fishbane and family of Boston, Massachusetts, and extended family, friends and colleagues. Leah was working on her doctoral dissertation in American Jewish History at Brandeis University under Professor Jonathan Sarna. She will be deeply missed. May her memory be for a blessing. A memorial fund will be established at the Jewish Theological Seminary.

HAVE A GREAT STORY OR WANT TO SHARE SOME INFORMATION?

We encourage all our members to submit articles or information that **MAY** be included in upcoming newsletters. Unfortunately, there will be times due to space and/or content that an article may not make it into our newsletter.

E-MAIL NEWSLETTER SUBMISSIONS TO: Caroline Furry
(dfurrywitt@netzero.com)

The editors reserve the right to make corrections/edits as appropriate. Original items may be used if properly credited. Copyrighted items must have the permission of the originating author. NEWSLETTER DEADLINES ARE: March 1 (Spring), June 1 (Summer), September 1 (Fall), and December 1 (Winter)

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