I took Lindsey to one of her many doctor visits this past Saturday. It always amazes (and exhausts) me when I think of all the time we spend visiting and consulting with the many health care professionals that are involved in her life (and I think she’s healthy). She has an ENT, audiologist, cardiologist, hematologist, pediatrician, ophthalmologist, and a dentist. All these professionals then order an array of x-rays, blood tests, cardiograms, hearing and vision tests.

I am a nurse practitioner and I feel confident keeping track of all appointments, results, and follow-ups. However, it is a difficult task and at times it’s hard to stay on track given life’s other commitments and curve balls. Of course, many of you know exactly what I’m talking about because many of our children have the burden of multiple medical challenges. When Lindsey was first born, the schedule of therapies and doctor appointments was daunting. Now that she’s older, it seems better, and the appointments are mostly annual follow-ups.

There are several resources to assist families and doctors with the schedule of needed screening tests that are specific to children and adults with Down syndrome. Health Care Guidelines have been published and are a great resource for every family and their doctor. Lindsey’s pediatrician keeps a copy in her chart so he can refer to them during visits. I encourage all families to take a look at these guidelines and offer a copy to your doctor as a tool to help keep your child’s health on track. On page 7, we have included a compilation of some considerations and resources that may help you navigate the complicated path of managing the health of your child.

In addition to these resources, there are many books that address the health concerns of people with Down syndrome. The UPS for DownS Resource Library has a copy of “Medical and Surgical Care for Children with Down Syndrome.” It can be checked out for two weeks at a time. For more information about the UPS for DownS Resource Library, contact Annie Quiroz at 847-985-0579 or Jamz710@cs.com.

Sandy Pazerunas
Co-Chair
UPPS for Downs

Special Needs Estate Planning

Are you concerned about the financial future of your child with special needs? Join us as we hear about Special Needs Estate Planning. Regardless of your economic bracket, there is a way to safeguard the financial future of your child.

Theresa M. Varnet has been an advocate for persons with disabilities for over 30 years. In addition to being a certified teacher, licensed social worker and a graduate of the DePaul University College of Law, Ms. Varnet is the parent of an adult daughter with a developmental disability. Ms. Varnet is also an active volunteer in the national, state and local chapters of the ARC.

She is a frequent speaker for volunteer and professional groups and has presented nationally. She also writes a regular column on “Future Planning” for Exceptional Parent magazine.

When: Tuesday, April 26, 2005
Location: Gigi’s Playhouse/UPS for DownS
1069 W. Golf Road; Hoffman Estate
Time: 7:30 p.m.

As always, you are welcome to bring others who might be interested in this topic to the meeting. Very limited child care is available. If you need child care, you MUST RSVP to Melinda at 847-466-9953 or MommyHasSpoken@aol.com before Monday, April 25th.

Please Note: UPS for Downs is a volunteer group consisting of parents, rather than educational, medical, or legal professionals. The UPS for Downs newsletter is similarly written on a volunteer, non-professional basis. Information presented in the newsletter should not be construed to be objective or definitive, but represents the opinions and understandings of the contributors. We are not responsible for reliance made on any information in this newsletter. We wish to bring together those interested in Down syndrome as we create and foster an optimistic outlook and attitude about Down syndrome for our families and our communities.
Parent participants in our March meeting were at full attention as Dr. Christopher Koch, the State Director of Special Education at the Illinois State Board of Education, spoke about No Child Left Behind (NCLB), Individuals with Disabilities Education Act (IDEA), and the role of the Illinois State Board of Education (ISBE) in implementing these laws.

The job of the Special Education Department of the ISBE is to insure IDEA’s implementation in Illinois. Districts are monitored through data provided by the district and complaints made by parents. Adequate yearly progress by special education students (as measured by ISAT tests) was not made in 210 districts in the state. Districts say the goals of NCLB, that ALL students are expected to improve and that by 2014 that 100% of students will achieve at the state defined “proficient” level on state reading and math academic assessments is unrealistic. Districts do not want special education students held to the same standards as regular education students. Dr. Koch stated that although in reality these goals might be unrealistic, it is good that the progress of ALL students is being scrutinized.

It is understood that even with accommodations, the ISAT is not an appropriate assessment for all students. The Illinois Alternate Assessment (IAA - a portfolio of student work) is an option. This assessment has acknowledged flaws; it is time consuming, cumbersome, and expensive, and may reflect more of the teacher’s ability to put it together than the student’s progress. On the other hand, ten years ago there wasn’t any alternative assessment or expectation to have a relatively objective measure for student progress which would hold school’s accountable for the education of students with more significant needs for whom the ISAT is an inappropriate tool. Only 1% of a districts students may take the IAA.

Historically, separate teacher training and separate facilities for special education students divided students with special needs from their regular education peers. One of the state goals is to increase the inclusion of students with special needs with their same age peers. This increases the focus on access to the general curriculum and offers access to more academic instruction and the same opportunities given to regular education students. This is not to say that functional curriculum does not have a place and is not appropriate for students with significant cognitive disabilities.

NEXT COFFEE AND PLAYGROUP

Are you new to United Parent Support for Down Syndrome? Are you new to the area? Do you just feel like getting together informally with other parents of kids with Ds? If the answer to any of those questions is yes, please join UPS for DownS for our monthly coffee and playgroup.

When: Saturday April 23 2005
Time: 10 a.m. to noon
Location: GiGi’s Playhouse; 1069 W. Golf Road; Hoffman Estates

the Parent Coffee and PlayGroup is held on the 4th Saturday of the month.

Questions about this month’s coffee?
Call Allison and Luis Vargas at 847-342-0041 or E-mail: info@upsfordowns.org

Congratulations to our New Parent Coordinators, Luis and Allison Vargas on the birth of Anthony Luis!
The Lords and Ladies of the PreTeenScene had a great time cheering on the blue knight at Medieval Times (although a few of the maternal chaperones seemed to be partial to the yellow knight)!

Feasting, falconry, jousting and swordplay kept the kids rapt with enjoyment.

Lady Rachel enjoys her soup as Lady Emily watches the action.

A squire is at the service of Lady Allie, Lady Julia, Lady Cristina, Lord Jack, and Lady Lindsey.

Lady Allie appears to consider Lord Jack her knight-in-shining-armor.

The knights prepare for competition.
Spring TeenScene Schedule

April 23 - Bingo and Bunco Night
May 14 - Out to the Movies
May 28 - Make a Summer T-Shirt
DATE CHANGE; June 4 - Bowling with the UPS for DownS Scotch Doubles Bowling
June 25 - Mexican Fiesta

Teen Scene is for teens with Down syndrome ages 12 to 18.
Teens pay $5 for each event; UPS for DownS pays for the rest!
Volunteers are welcomed and appreciated.
Activities are subject to change.
RSVP to pfogarty@wownway.com or call Peggy Grunewald at 847-359-3394

Katie MacDonald Literacy Project

Calling all marathon runners, calling all marathon runners - it is not too late to join Katie's Team Literacy to run in the October, 2005, Chicago Marathon and collect pledges for the Katie MacDonald Literacy Project. If you are planning on running and would consider collecting pledges, contact Shari Andress at 847-891-6678 or Nancy MacDonald at 847-392-2812 for more information.

Mark your calendars for the next book making workshop:

Date: Thursday, April 28, 2005
Time: 7:00 - 8:30
Location: GiGi's Playhouse

These book making workshops provide an opportunity for you to create relevant and meaningful material for your child to read. Bring your ideas and some photos of your child's favorite things - we'll help you with the rest. Sample books can be found in the UPS For DownS Resource library. Workshops are not limited to parents - one mom is bringing her child's resource teacher along for the evening - what a great idea! If you have any questions, be sure to ask when you RSVP to Shari at 847-891-6678 or skandress@aol.com.

UPS FOR DOWNS IS COMMITTED TO PROVIDING ONGOING LITERACY-BASED PROJECTS TO HONOR THE MEMORY OF KATIE MACDONALD AND HER LOVE OF READING.

UPS for DownS is heading to the toilet!

Join us for a presentation on toilet-training with our favorite behavior expert, Alice Belgrade

When: 9 a.m. - Noon on Saturday, April 30, 2005
Location: Alexian Brothers Medical Center
Elk Grove Village, Illinois
Cost: $5.00

The straight poop - and a registration form - may be downloaded at: www.upsfordowns.org/events.htm
The Arc of Illinois administers The Consumer Involvement Fund Program and distributes consumer stipends to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues.

HOW MUCH CAN I APPLY FOR?
• $300 per person per year
• $500 per family per year
• Consumers are expected to participate in cost sharing and contribute 50% or more of the total costs of the conference or to provide a reason why they cannot do so.

WHO CAN APPLY?
• Illinois resident
• A person with a developmental disability
• A parent of a person with a developmental disability

WHAT CAN I APPLY FOR?
• Conference must be directly related to developmental disabilities
• Conference Registration
• Child Care
• Respite Care
• Meals, Hotel, Transportation

Any Questions? Call 708/206-1930
Download the registration form at www.thearcofil.org
Finding a method to manage and monitor the health care needs of your child with Down syndrome can be overwhelming. Coupled with inevitable insurance snafus, educational turmoil, and the general mayhem involved in raising a family, it can seem insurmountable.

There are some basics that parents recognize need to be addressed, but eventually, the timing can be confusing. Be certain that your pediatrician has the appropriate growth chart - specific to children with Down syndrome - for height, weight and head circumference.

Evaluation by a pediatric cardiologist as a newborn, should include an echocardiogram
Ophthalmology at 6 and 12 months
Thyroid screening at 6 and 12 months, then annually
Hearing evaluations at birth, and every 6 months thereafter until 3 years; then annually
Celiac disease screening between 2 and 3 years of age
C-Spine x-ray for atlanto-axial instability - once between 3 and 5 years, and as needed for Special Olympics

Some specialists that might, at some time, be involved in addressing your child’s medical needs could include:

- audiologist
- cardiologist
- geneticist
- gastroenterologist
- ENT
- ophthalmologist
- endocrinologist
- urologist
- hematologist
- neurologist
- pediatric dentist
- orthopedic doctor
- physical therapist
- occupational therapist
- speech pathologist

One of the most comprehensive websites with numerous medical abstracts and resources specific to medical issues is **www.ds-health.com**. This website is the product of Len Leshin, M.D., pediatrician and father of a preteen with Down syndrome. The mission statement says:

> The mission of this website is to promote the health of children with Down syndrome and to empower parents of children with Down syndrome with knowledge about the condition. This goal is to be achieved by providing information to readers in the form of essays by Dr. Leshin and other people knowledgeable about Down syndrome, reviews of scientific research about Down syndrome, and other important information such as internet sites and books.

The very helpful Down Syndrome Health Care Guidelines Record Sheet - a checklist form - is available for download from Dr. Leshin’s site: **www.ds-health.com**.

**Dr. Brian Chicoine has prepared a variety of materials for providing health care to adults with Down syndrome. These include history questionnaires, review of systems checklists, physical examination forms and an assessment/plan form which includes screening information. For more information, contact the Adult Down Syndrome Clinic at Lutheran General Hospital, 1999 Dempster Street; Park Ridge, Illinois 60068; 847-318-2303.**

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**Looking Ahead:**

**Grandparent Meeting**

**MAY 24 2005**

Diane Gould will facilitate a special meeting for grandparents and “surrogate” grandparents. This meeting will provide a forum for them to share their joys, concerns and insights about loving someone with Down syndrome.

**Annual Dinner Meeting**

**June 28 2005**

Join us with your ideas as we plan ahead for next year’s events, meetings and activities. Location TBA
Becky and Alex C. will be hosting Kids’ Club open play

Saturday, April 16, 2005

New time for April only: 12:30 p.m. - 2:00 p.m.

Saturday, May 21, 2005
Time: 1 - 2:30 p.m.

We will be working on some special projects for those in the Armed Forces to commemorate Armed Forces Day.
If you have a special someone who has or is serving in the Armed Forces, please invite them to join us on this day.

Contact Shari Andress for more information.
847-891-6678  skandress@aol.com

Kids’ Club is designed for preschoolers and early elementary age children with Down Syndrome and their siblings!

PreteenScene

Please RSVP to Lori Boldt at LoriBoldt@hotmail.com or (847) 818-1714 for the following activities.

Swimming at Elk Grove Pavilion

Date: Sunday, April 24th
Time: 4:30 - 7:00 p.m.
Location: Elk Grove Pavilion Aquatic Center
Swimming: 4:45 - 6 p.m.
Party room/food: 6 - 6:45 p.m.

Pizza Party!

Date: Sunday, May 22nd
Time: 4 p.m. - 6 p.m.
Location: Barnaby’s Family Inn (dairy free pizza available)
134 W Golf Rd.
Schaumburg
(847) 882-3220

"Where the Wild Things Are"
followed by a picnic lunch weather permitting

Date: Sunday, June 26th
Time: 11:00 a.m.
Location: Arlington Heights Metropolis Theater

As tickets must be purchased in advance, you MUST RSVP BEFORE April 24th

PreteenScene is for kids in 3rd grade through 6th grade (up to age 12) with Down syndrome and their siblings who are also in that age group. Events in the community require a parent/adult chaperone to remain with the group. We ask that, when possible, alternate arrangements be made for younger children to allow for better facilitation for the Preteen’s activities.
What does the state do when districts don’t behave? First, Dr. Koch assured us that most teachers, principals, schools, and districts do want to be in compliance.

Dr. Koch stated that the number one reason parents seek intervention from ISBE is that they were disrespected by school personnel. He says that he sees this time and again and it is exasperating that so many educators treat parents with less than common courtesy and respect. Clearly, we are all emotional about "our" kids, whether as parents or educators, but those very emotions engendered by being treated unfairly can make it difficult to think through the situation and adequately formulate the issues. Often, parents seek a resolution or ask for things that aren't allowed under the law, for example, the firing of teachers or school personnel.

There are three methods in which to involve the Illinois State Board of Education to resolve a dispute:
1. Complaint system;
2. Mediation system;
3. Due Process system.

One alternative for parents is to file a complaint with ISBE. After receiving a complaint, the state board has sixty (60) days to investigate. The complaint system is distinct from the Due Process System. It is best used when there is a clear violation. One parent said that they utilized the complaint process on a narrow transportation issue and were surprised with the speedy resolution and more than satisfied with the outcome.

A valid complaint might be that the student is not getting a service stated in the IEP. If the district is in error, immediate and compensatory services are required. Other leverages the state board has over districts to ensure compliance are money and public perception. State and federal money can be withheld from districts not in compliance, though that is problematic because ultimately, withholding funds impacts the very students it is intended to assist. Districts care very much about their reputation in the public eye, and do not want bad publicity.

Parents have a wealth of information at their fingertips via the Internet. The Illinois State Board of Education website (www.isbe.net) provides a way for parents to view their district’s Special Education Profile - data on special education student enrollment, performance on state assessments, and their educational environment (LRE data). The district data is compared with state data. Under Dr. Koch’s leadership, this information has been made readily available to the public, and allows comparison between districts to see how they are perform against state and federal benchmarks for improvement.

ISBE is required to have an improvement plan for special education on file with the Office of Special Education Programs and the U.S. Department of Education. There are five over-arching goals of the Illinois’ plan (which is available for download from www.isbe.net/spec-ed):
1. Increase the graduation rate among students with disabilities;
2. Improve the numbers of students who are being educated in the least restrictive environment;
3. Provide for adequate highly qualified personnel in the delivery of special education in Illinois;
4. Increase meaningful parental involvement in the delivery of special education services;
5. Ensure that compliance and monitoring system of local education agencies (local districts) is meaningful and effective.

Dr. Koch assured us, that as parents, we do have power. Relationships are key in the business of education, and the state board is working toward helping parents and school personnel communicate effectively and solve problems for the benefit of students. Parents may contact the ISBE via email, snail mail, and phone.

The overwhelming positive response to this meeting resulted in the decision to conduct a workshop in the fall which will enable further discussion and more in-depth analysis of these topics. Watch for further information in your newsletter!

Christopher Koch, Ed.D.
Assistant Superintendent for Special Education
Illinois State Board of Education
100 N. First Street
Springfield, IL 62777
217/782-4870 Springfield
312/814-8498 Chicago

O.K....I know it is wrong to stereotype but I was expecting the Director of Special Ed of the State of Illinois to be an "Old Geezer" type, who just cared about the administrative side and did not care about the kids. Boy was I shocked! He was so insightful, compassionate, approachable and realistic....I LOVED him and what he had to say.

-Cindy H. meeting participant
Information about our upcoming Scotch Doubles Bowling fundraiser is scattered throughout this newsletter. Enclosed are raffle tickets, information about how to get more raffle tickets and a registration form for bowling. On page 11 is and information sheet for you to copy and share with friends, family or neighbors who may wish to join you in supporting UPS for DownS at this fun event.

If you or a business owner that you know would like to donate a prize for our raffle, please contact Stacy Graves at 847-608-9781 or cs-graves@comcast.net. Stacy will help make necessary arrangements or will send a donation request letter from UPS for DownS to merchants that you suggest.

It’s time for our last Bowling Event planning meeting. We will be getting raffle tickets ready for the event and can use your help! Please join us. This is a fun and relaxing way to get to know others in this group.

When: Friday, May 13th, 2005 at 7:00pm
Location: GiGi’s Playhouse / UPS for DownS office

Please reply to Diane Paradise at 630-483-8113 or Stacy Graves at 847-608-9781 or email: bowling@upsfordowns.org
UPS for DownS
United Parent Support for Down Syndrome
Scotch Doubles Bowling Night

I am bowling for: _________________________
(name of person with Down syndrome)

Your name (or contact person): _________________________

Address: ______________________________________
____________________________________

Phone Number: ______________ E-mail Address: ______________

Saturday, June 4th, 2005
Buffet Dinner at 5 p.m.
Bowling promptly at 6 p.m.

Enclosed is my payment for the following couples:
1. _________________________
2. _________________________
3. _________________________
4. _________________________
5. _________________________

I would like to purchase ____ tickets for the
Bowling Fundraiser at $45 each (per couple). $_______

I would like to purchase ____ raffle tickets
($5.00 for a book of 6 or $1.00 each). Additional
tickets can be sent to you upon request. $_______

I can’t attend, but would like to donate: $_______

Total amount enclosed $_______

Mail to: UPS for DownS, c/o Diane Paradise, 1408 White Fence Road, Bartlett, IL 60103,
Questions? Contact Diane at: 630-483-8113 or Bowling@upsfordowns.org
Nickname: Dews (as in Dewli a)

Favorite thing about school: Reading and math and Mikayla and Mrs West. Next year, Mikayla wants me to take the regular bus to school so we can sit together. Oh yeah, oh yeah it's gonna be so cool, we are going to sit in the back!!

Last book read: The Old Lady Who Wasn't Afraid of Anything

Hobby: PlayStation. Spyro is my favorite

Favorite movie(s): Shrek 2; Princess Diaries 2

Favorite food: Chicken Nuggets, Pizza, Fries

Latest Accomplishment: I can zip my coat all by myself and I can swallow pills, too. My cousin Nina still can't swallow pills.

Quote: My sister Anna is a really cool person. She is growing out her bangs.

Occupation: Fourth grader, special olympic athlete, school mail girl

Date of Birth: December 29, 1994