

DSAA Today

The Newsletter of the Down Syndrome Association of Atlanta • November 2005

Governor Sonny Perdue Proclaims October Down Syndrome Awareness Month for Georgia

By Heidi J. Moore

On October 4, 2005, Governor Sonny Perdue proclaimed October to be Down Syndrome Awareness Month for the State of Georgia. More than 50 family and friends attended the signing by Governor Perdue and participated in a photo opportunity that took place at the steps in the rotunda of the state capitol building. The local CBS news affiliate channel 46 even had a segment on the event the day after and gave us some additional coverage on our upcoming Buddy

Walk! I personally want to thank Susan Lumpkin for helping make this event happen. Only through education and awareness are we going to be able to help the community understand what the true potential is for our children! Please take a moment to send a thank you to Governor Perdue (Georgia.Governor@gov.state.ga.us) expressing your support of the event and acknowledge his efforts. *Read the proclamation on page 5.*



DSAA families gather on the main stairs in the capitol building with Senator Dan Moody, Governor Sonny Perdue, and National Down Syndrome Congress Executive Director, David Tolleson (seated in the front row from left to right).



Governor Sonny Perdue addressing the families during the proclamation ceremony.



Governor Perdue with Susan Lumpkin, DSAA member who organized this event, her son Zachary, displaying the proclamation, and daughters Zoe and Zana.

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From the Executive Director



My name is Michelle Norweck and it is an honor and a privilege to introduce myself as your new Executive Director. I became a member of the Down Syndrome Association of Atlanta two years ago following the birth of my second son, Christopher. As many of you have experienced, learning that my child would be born with Down syndrome was an overwhelming life experience

filled with fear of the unknown and much uncertainty. The initial news quite honestly was devastating to my husband and me. Now, being able to reflect back on life's journey and then fast forward to today, I have a remarkable feeling of pride as I look at my two-year-old son filled with curiosity, endless joy, and a contagious laugh. Christopher amazes me everyday with the funny things he does and all of the typical things that he can do. The support received from family and friends was tremendously helpful, but hearing other people's stories and experiences—other parents of children with Down syndrome—is what turned my fears and anxiety into calm enlightenment. Being a Licensed Clinical Social Worker, I have received years of training on empathy and social support systems. However, there is no support like that which comes from someone who's "been there." The Down Syndrome Association of Atlanta has become a constant source

of support to my family and me. The social events, newsletters, and educational seminars have helped to give us a foundation from which we have built a strong knowledge base and support network. Just when I think I have every book on Down syndrome or researched every community resource, I connect with a monthly DS playgroup and find out about something new from another family who's a little further along on their life's journey.

I truly believe that there are a series of events in life that are set in motion and lead each of us on our unique path and that we are called to be who we are by way of this journey. I am very fortunate and grateful to be called to the Executive Director position of the Down Syndrome Association of Atlanta. I look forward to promoting public awareness and helping to educate the community about Down syndrome. I believe in the empowering of other parents of children with Down syndrome through supportive counseling and informing them about public policy and legislation affecting people with developmental disabilities. I will also work closely with teaching institutions to ensure research is supported and advocated for programs that enhance the lives of our adult children with Down syndrome. I look forward to meeting and talking with many of you over the upcoming weeks and months and I encourage you to contact me with any questions, concerns, and suggestions. Thank you for being a member and supporting the Down Syndrome Association of Atlanta. Your membership and active participation is something for which you can be very proud.

Sincerely, *Michelle Norweck*

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Advocacy Update

By Heidi J. Moore, DSAA Advocacy Director

Here is a revised understanding of what some of the issues are regarding the Katie Beckett Waiver at this time and helpful hints. Based on the 100+ families I have been in contact with over the last few months, there has been a huge increase in Katie Beckett Waiver denials in Georgia!

I'm aware that there are a lot of questions regarding the KB Waiver as more and more families are being denied. I've compiled the following information in the hope of answering some of your questions. This information is based on my discussion with advocates, DCH, providers, legislators and families. As always, I must state that I'm only a parent that happens to be an advocate for our children, NOT an expert.

1. There has been an **increase in KB Waiver denials** since May 2005: No specific disability has been targeted. (All KB applications dated 11/15/04 or later are following new guidelines).

2. You can review the new **eligibility guidelines for the KB waiver on the web.** Go to www.communityhealth.state.ga.us, click on "Medicaid," then click on "New Information on TEFRA/Katie Beckett & Required Forms." This is where you will find letters from DCH, the New DMA-6A form, instructions, Level of Care Criteria (this means new eligibility requirements), the Care Plan and Instructions.

3. All applications after 11/15/04 have the following new forms:
a. Pediatric DMA6(A).
b. Care Plan (DMA706).
c. Cost-Effectiveness Form (DMA704 that replaced the Deeming Waiver Physicians Referral Form).

4. Fill out all the forms as a "Provider" NOT as a "parent."

5. DCH is currently reviewing applications that were submitted in April 2005.

6. Submit ALL the forms in your application together in one package if possible.

7. If you are denied, you should contact the Governor's Council on Developmental Disabilities (GCDD) so they can keep track of those denials. If your family has been denied or is appealing or has appealed and

been reinstated to the Katie Beckett waiver, PLEASE give Pat Nobbie, via e-mail (pnobbie@dhr.state.ga.us), the

following information:

- A. Child's condition and a brief statement of their needs, and how your child benefits from the services available under the waiver.
- B. How long you have been on the waiver.
- C. Whether you have primary insurance.
- D. If you have been rejected upon reauthorization.
- E. If rejected, the reason given on the letter of denial.
- F. If you are appealing.
- G. If you have appealed, are you still being covered, and how long you have waited for a decision, or expect to wait.
- H. The impact that rejection will have on your family.
- I. Any other special circumstances; for example, being told to drop your primary insurance, being told there was a waiting list for Katie Beckett, etc.

8. ALWAYS send everything to GA Health Partners/DCH by certified mail and returned receipt so you have a record of them receiving it.

9. If a family is denied the KB waiver (in the renewal process) and receives the certified letter stating so; the child will stay on Medicaid during the appeal process BUT if the department prevails the family **could be liable for the coverage provided during the appeal process.** If the family is a new applicant, they would receive no coverage during the appeal process.

10. Tips for Appeals:

- a. Resubmit any Medicaid documents that you feel you may have not filled out properly based on the new eligibility guidelines.
- b. Prepare a 24-hour Care Plan going into detail about your child's day from the time they get up to the time they go to sleep. Explain everything you do as a parent that goes beyond "typical" child duties as a parent.
- c. Have all your doctors, therapists, and any other professionals that work with your child submit a letter explaining why your child needs the waiver.

Other Information:

Contact your legislators and let them know how this impacts your family. Stress that you are a tax paying, voting citizen and the only way your child will be able to

achieve success in the future is through early intervention services and medical care now. You can find your State Senator and Representative by going to www.vote-smart.org and inputting your zip code. We need to help educate those that represent us at the Capitol!

Get involved and **monitor your child's Medicaid card.** Go to the following website: www.ghp.georgia.gov and request a password from Georgia Health Partnership (they manage the program) to access and track Medicaid charges to your child's account. This is **very important** in order to verify and report problems on your child's Medicaid account. If you find that there are problems or concerns regarding your child's Medicaid account you can file a complaint via the website above then go to "Member information" and click on "Fraud and Abuse" or call 1.800.533.0686 or 404.206.6480. Only through education, accountability and communication are we going to be able to make a difference in the process.

The Governor's office is currently looking at reforming the entire Medicaid population (including the KB Waiver). A lot of the same issues we have faced in advocacy over the last three years, are being reviewed by the formation of six committees. Katie Beckett Waivers are just one of many "groups" that receive Medicaid services being reviewed. It is my understanding that there will be an open public commitment period in December 2005 regarding the Governor's Medicaid plan. Once again, **the only way we are going to be able to impact change is by advocating for our children's rights and helping to educate the government on the "real" issues involved with this special population of consumers!**

I will keep you posted on what this means from an advocacy standpoint and how it effects us after details are released. The subcommittees are still meeting and putting together recommendations with a draft proposal that potentially could be completed by the end of November. The Governor plans on submitting his final recommendations to the General Assembly sometime this next legislative session starting in January 2006.

Get Involved! Advocating is the key to success in getting the services we need for our children. If you would like to be placed on my advocacy distribution list, please e-mail me at heidijmoore@comcast.net. My goal is: **Make the issues easy to understand and explain to advocates what they can do to influence change in this State!** United.....WE will make a Difference!

DSAA Recap



A big THANK YOU to our Buddy Walk Sponsors:

Etowah High School
 Southeastern Hose, Inc.
 Sharon Elementary
 Kroger Pharmacy
 An Early Start, P.C.
 Helping Hands, Inc.
 Nana & Papaw Biggs
 Kidsplay Therapy Center
 Settles Bridge Elementary
 Frank Betz & Associates
 Metdesk
 HR Works
 ASR Computer
 Kiddo's Clubhouse
 Brasfield & Gorrie
 Kids Creek Pediatric Therapy
 Pediatric Therapy of Forsyth
 Kool Kidz, Inc.
 (Children's Therapy Services)
 TLC
 Merced Tile
 Lazerquick
 W.M. Grocery
 Optimus Solutions
 N.Y. City Deli & Bagels
 Marketing Incentives
 Jeannie Visootsak, M.D.
 Allgood Pest Solutions
 N.Y. Police Benevolent Assoc.
 Children's Healthcare of Atlanta
 Allegrow
 911wear.com
 Hyde Academy
 Small Town Bank
 Pioneer Group, Inc.
 atlantasbestdj.com
 Sonia George-Bussey, M.D.
 Meadows Farm Equipment
 magicmanentertainment.com
 Atlanta Journal/Constitution

Buddy Walk 2005



By Lauren Biggs & Diane Bromelow

WOW! is the first word that comes to mind when we think of the Buddy Walk on Saturday, October 15th. It was great to look around and see all the happy people singing, dancing, hugging, splashing, bouncing, cake-walking, and winning! We did a lot more than just walk. The turnout was unbelievable. Between 1,200 and 1,500 people at one time were there to support our beautiful children and raise funds to help our organization make a difference. More than \$63,000 has been raised, and the checks are still coming in!

We had some great food provided by Harry's Farmers Market of Gwinnett and music from Neal Howard, our DJ extraordinaire. The silent auction and raffle featured many items provided by local businesses and celebrities. The whistle band, lead by music therapist Ginger Bennett, was a fun activity for all to enjoy. The moonwalks were provided by Kids Creek therapy with therapists themselves supervising adults and children alike to keep all having fun while staying safe. Pediatric Therapy of Forsyth provided popcorn, spin art, and storytelling. Jessica Cook and Stefanie Baumblatt were in charge of cooking up loads of fun with the Cakewalk. Two local Brownie troops ("buddies" of Caitlin Merriam and Lainey Carroll) were serving water and Kool Aid to the thirsty masses. South Forsyth High School's Beta Club did

Buddy Walk continues on page 5.



Down Syndrome Awareness Month Official Proclamation

WHEREAS: Down Syndrome is a commonly occurring chromosomal abnormality, resulting when a person possesses three, rather than the usual two, copies of the 21st chromosome. About 5,000 babies per year are born with Down Syndrome. Over 350,000 people in the United States have Down Syndrome, of which 9,500 live in Georgia; and

WHEREAS: Down Syndrome affects individuals of all races and economic levels. Those with Down Syndrome have some degree of cognitive delay, ranging from mild to moderate. There may be common facial characteristics as well as related medical conditions. People with Down Syndrome are unique individuals that may possess these characteristics to different degrees or not at all; and

WHEREAS: Children with Down Syndrome raised at home and included in all aspects of community life can best reach their potential and function in society with a greater degree of independence. Parental love and nurturing, early intervention programs, educational opportunities and community involvement help a person with Down Syndrome achieve his or her potential; and

WHEREAS: Research and early intervention have resulted in outstanding improvements in the length and quality of life of individuals with Down Syndrome; however, continued efforts in genetic research may help improve, correct or prevent some of the challenges associated with Down Syndrome; and

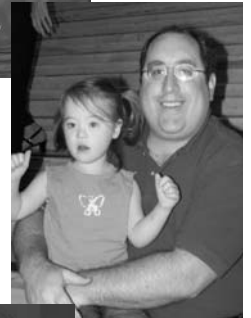
WHEREAS: During the month of October, advocacy groups and non-profit organizations will work to educate the public about Down Syndrome, encouraging acceptance and inclusion of individuals with the syndrome. It is in the interest of the state to recognize the achievements in this field and to continue these efforts; now

THEREFORE: I, SONNY PERDUE, Governor of the State of Georgia, do hereby proclaim October, 2005, as DOWN SYNDROME AWARENESS MONTH in Georgia.

In witness thereof, I have hereunto set my hand and caused the Seal of the Executive Department to be affixed this fourth day of October in the year of our Lord two thousand five.



A few more photos from the Proclamation Ceremony.



Buddy Walk

Continued from page 4.

a great job tattooing everyone who stopped by. We also had many Buddy Walkers who had some crazy colored hair as well!! The walk itself was lead by the South Forsyth Middle School band. They did a wonderful job leading the parade as traffic was stopped on GA 120 for our huge group to pass. All the sponsors listed on the back of the Buddy Walk shirts were instrumental in making the event a success. Please take a chance to thank them if you see them.

As we complete our two-year term as "DSAA's Buddy Walk Co-Chairs" we want to thank everyone who helped make this day great. If you baked a cake, helped collect items for the silent auction or raffle, or gave a "heads-up" for a potential sponsor, THANK YOU. If you came on the big day and supported the festivities, THANK YOU! We look forward to many more years of fun events with our friends of the DSAA; it is a wonderful group of people.

What's Coming Up

DSAA HOLIDAY PARTY

Join us for brunch with Santa, Saturday, December 3, 2005. We will be meeting at Winfield Hall, 3890 Satellite Blvd., in Duluth from 11:00 a.m. - 1:00p.m. This non-ecumenical party will feature great food, music, Santa, gifts for the children, and more. We hope to see you there! To reserve your spot, please send check (payable to DSAA) for \$10 per family of four. Please add \$2 for each additional person along with your name, address, phone number, children's ages to **Shere' Owens**, 4815 Brandon Acres Lane, Buford, GA 30519.



THE EMORY CONNECTION

What's New with the Emory Down Syndrome Clinic

By Dr. Jeannie Visootsak

It has been a year and a half since I joined the Emory Down Syndrome Clinic. I am now past my infancy period and look forward with great enthusiasm to the next stage. I have learned so much from the families who have come to clinic. This is the type of learning that does not come from textbooks or lectures. My interactions with parents have affirmed how important it is for us to make each clinic visit a family affair.

We have started two programs with the support of the March of Dimes (MOD) and American Academy of Pediatrics (AAP). First, our MOD project "Down Syndrome Parent and Education Support Program" allows us to provide up-to-date educational and resource material for parents of newborns with Down syndrome. We have purchased several books and videotapes that parents can browse when they are in clinic.

In addition, we have also been awarded the AAP Community Access to Child Health (CATCH) grant to "CATCH UP WITH DOWN." The funds are earmarked for projects that will increase community awareness of the Emory Down Syndrome Clinic and ensure that we are reaching all parts of the population. In addition, because the AAP promotes the idea of a "medical home," we plan to use questionnaires and focus groups to seek input from families on how our clinic can best grow to serve them and their child.

I'll close with some notes about our clinic team's summer activities. We found time to tour the dentistry and therapy facilities at Children's Healthcare of Atlanta at Scottish Rite to find out what they have to offer. We also had an informal meeting with an occupational therapist from Babies Can't Wait to learn more about their program and services. I attended my first summer camp, CAMP C.A.M.P. (Children's Association for Maximum Potential), in San Antonio, Texas. The opportunity allowed me to see children outside the clinical setting and understand what parents experience 24/7. These children had so much energy !!

We thank all of the families who have taken the time to come see us in clinic. We look forward to seeing you again!

Jeannie Visootsak, MD, FAAP is a Developmental Pediatrician and Medical Director of the Emory Down Syndrome Clinic For information about the clinic which serves children from birth to age 3 years, please contact our clinic coordinator, Aimee Anido, MS (404-778-8481, aanido@genetics.emory.edu) or Sallie Freeman, PhD (404-778-8484; sfreeman@genetics.emory.edu).

Evan Dewey - School Spirit Superlative



Evan Dewey was recently voted by the Senior Class at Tucker High School the Senior Superlative of "Most Tucker High School Spirit" - male. Evan will graduate in May, and in addition to his football manager responsibilities at THS, he is currently attending one of the DeKalb County School system's Transition Programs housed at Mercer University.

Evan has been a football manager for the Tucker Tigers for four years. Tucker has produced some of the best football talent in the state and has been in the playoffs all four years Evan has been a manager. Evan travels with the team to all the games. One of Evan's highlights as a manager was working the semifinal match against Statesboro in the Georgia Dome.

His enthusiastic spirit has won over many a Tucker fan. Evan is very honored by this superlative title.

Asociacion Hispana de Sindrome de Down de Atlanta (AHSDA) Celebrates 5th Anniversary!

By Susy Martorell and Zoila Martinez

AHSDA is pleased and proud to proclaim that September 2005 marks five years since we began our support group for Spanish speaking families in Georgia! AHSDA is the only support group of its kind in the United States, culturally and linguistically programmed, to serve Spanish-speaking families with children with Down syndrome. From modest beginnings with the first meeting of twelve families in September 2000, we now have over 150 Spanish speaking families referred to the Down Syndrome Association of

Atlanta's Spanish support group.

AHSDA continues to meet one Thursday each month, September through May, with an average attendance of 16 to 18 families at each meeting. Parents get an opportunity to meet others with similar concerns, support one another, and learn more about Down syndrome. We bring in speakers at each meeting to present pertinent information that will help the member parents be more successful in their efforts to nurture and parent their children with Down syndrome.

Our September meeting was particularly exciting as it combined a speaker from the

community, Nancy Duncan, as well as the initiation of an idea that originated with one of our AHSDA mothers, Lourdes Flores. The meeting began as it always does, with introductions around the room; mothers heralded from Mexico, Honduras, Peru, Colombia, and Nicaragua. Nancy Duncan, Director of the Georgia ADA Exchange, shared experiences of her life as a blind person with the assembled group. She told the mothers that growing up with a disability did not keep her from having dreams and plans for the future. She wanted a family and a full life and succeeded on both counts. Answering a parent's question on what gave her the strength to pursue her dreams, Nancy remarked that

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The Ingrams join DSAA, welcome!

By Sharon Jones Baron, DSAA Newsletter Editor

I wanted to take this opportunity to introduce everyone at DSAA to one of our newest member families, David, Christie, and Carly Ingram. The Ingrams joined DSAA this year and come to us in a more non-traditional way, they adopted! I had an opportunity to interview them and here is their story.

Part one of the story:

Christie and David had been trying to have children for some time and like many couples these days having a child of their own was eluding them. They were open to adoption and decided they would like to adopt a baby from Guatemala. They went through the entire process and were given the opportunity to adopt a baby girl, only to have their hopes slashed at the last minute by the birth mother who changed her mind. This was such an emotional time in their lives, and once again the blessings of having a family eluded them. David and Christie credit their faith and prayer for getting them through this difficult time.

Part two of the story:

Christie's sister-in-law, through her county school program, became aware of a newborn baby girl with Down syndrome that was in need of being adopted. Christie said that once again they turned to God and let their faith guide the way. Christie and David decided they wanted this baby girl to be part of their family; with excitement in their hearts they started the interview process.

Let me pause it here, and give you a little more information about Christie and her wonderful Mom credentials. During her college years she was a nanny to a family with multiple children and one of the children had Down syndrome. She is a teacher by profession and most recently was teaching Special Education. All of her large extended family, as well as David's live right here in town, and they were all in support of the decision to adopt this newborn girl. Christie was even willing to put her teaching career on hold to be a stay-at-home mom.



Carly Ingram striking a pose.

"From, Dave and Christie's point of view "it was a perfect fit from the start."

And now, back to the story. During the first adoption interview David and Christie had an opportunity to meet the baby girl and hold her, there was an instant bond, and they knew they had been led to this baby. In their hearts they felt that their hope of finally having a child was going to happen. From David and Christie's point of view it was a perfect fit from the start. However they were stunned to find out they were one of six families being interviewed to adopt the baby-dashed hopes, more prayer, and a few more endless weeks of waiting for the Ingrams.

Part three of the story:

Baby Carly finds a home and David and Christie are finally parents! Needless to say David and Christie were thrilled beyond their wildest hopes when they were selected. Carly had some medical challenges with two major surgeries during her first six months of life, but she has come through everything beautifully and Mom reports that Carly feels the best she has in months.

Christie and David are so thankful for the support they have received from the Down syndrome community—the meals, phone calls, and advice. Some of you may have even seen the Ingrams at the Buddy Walk just a few weeks ago.

... and there is more:

Carly is going to be a big sister! Another baby girl in Guatemala is in need of a home and Christie and David have decided to adopt her, and all seems to be going well this time around. Carly and the new baby will only be six weeks apart in age, practically twins! AND to top-off this amazing year, Christie just found out she is pregnant—a wonderful and blessed end to this part of the Ingram's incredible journey.

AHSDA

Continued from page 6.

family support, especially her grandmother's belief in her, made a critical difference. Nancy also brought the message of disability rights to the group, encouraging parents to make sure that doors are not closed to their kids because of their disability, to know their rights and to be their child's best advocate!

The second half of the meeting was turned over to Lourdes who led a "play-group" session for parents to play, sing, and relax with their children, while they chatted and got to know one another better. Moms on the floor with babies soon led to women sharing stories of worries, lack of support from family members, and finding the strength to move forward even when things look bleak. Genessey from Honduras, said that she was determined to do the best possible for her baby girl, with or without help. She has been an active AHSDA participant since Danna Lisette was born last January, quickly learning how to encourage others. We plan to repeat the play group sessions throughout the monthly meetings to continue to provide parents with the chance to share their concerns and support one another. Thanks to Lourdes for this excellent idea!

Holiday Highlights

Girls Night Out!

Kick-off your Christmas shopping at The Chandlery in downtown Roswell. Enjoy wine and cheese, have fun with your girl friends, and help raise money for the Down Syndrome Association of Atlanta.

**Friday, December 2, 2005
from 6:30-9:00 p.m.**

The Chandlery, located at 950 Canton Street, is an extraordinary gift shop with one-of-a-kind gifts; you can even pre-purchase Radko ornaments to be signed by an ambassador of Radko the following week. The Chandlery will donate ten percent of our purchases back to the DSAA. Invite your friends, family, therapists, etc. to join us.

RSVP to Jennifer Carroll at
jenniferofroswell@msn.com, or
770.998.1703 by
Friday, November 25.

BIRTHDAY GREETINGS TO

November Birthdays

Jeremy Ahn
Nadia Arriola
Camilo Barrera
Severinao Chavez
Angela Clark
Mitch Dillon
Kayla Evans
Carter Forman
John Garcia
Katie Gilbert
Dior Gilbert

Matthew Hayes
Emma Henley
Rachel Hunter
Jake King
Johnathan Lanning
Bryant Lo
Megan MacArthur
Kevin Mackey
Guadalupe Mancha
Bernardo Martinez
Ashley McCormick
Scott McKenney
Johnathan McKinley
Jack Prettyman
Haley Price
Joshua Roberts
Amy Rogers
Cristian Rogers
Russ Silver
James Smith
Rylan Turpin

Miriam Vargas
Jonathan Alex Whiteman
Donna Williams

December Birthdays

Dylan Allen
Jack Anderson
Jamie Anderson
Cyndi Barreto
Kristina Brewster
Kenley Coleman
Lola Pick
Kaleb Dixon
Kevin Wilburn
Emma Dymek
David Evans
Taylor Freeman
Ismael Goicochea
Marti Grieco
John Gross
Maddie Harrison
Matthew Harrison

Cesar Hernandez
Nalini Isaac
Andrew Kern
Kelly Knowles
Jill Kuniansky
AJ Leverett
Evan Long
Owen Mauldin
Drew McClanahan
Ana Maria Nava
Courtney Owens
Justin Price
Cesar Quirasco
Kie Sikes
Marlen Silverio
Melissa Smith
Christopher Smith
Victoria Sobowale
Hannah Turner
Kameron Wheeler
Michael Wright

DSAA Today



Meet the Ingram family,
new DSAA members!
See page 7.

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Statement of disclaimer: The editor of this newsletter writes as a non-professional. This newsletter reports items of interest relating to Down syndrome. The Association does not promote or recommend any therapy, treatment, etc. We wish to bring together those interested in Down syndrome.