



B.U.D.S.

Bringing Up Down Syndrome

Quarterly Newsletter

Volume 11, Issue III

Spring Issue — April 2006

Embarking on Another Journey – Lin Rubright



input or help - just step in. As past officers (and knowing the current offers) - help is not something BUDS turn away! No idea is too little, too silly or too easy to go undiscussed. If you have something you want to bring to the

Inside this issue:

BUDS Events	2
BUDS Buddy Walk	3
On Raising Becca ~ by Shelly Garner	4-5
Teens For Teens ~ by Jillian Hagner	6-7
To The Editor by Shelly Garner	8
Great Things Happening!	9
List of Area Events (provided by SPAN)	10
BUDS B-Ball & Websites to Use	11

No, we are not having another child! :-) The Rubrights are making an attempt to fill the rather large shoes of Sue Schuitema by being Chairperson and Sponsorship Chair of this year's BUDS Buddy Walk. In an effort to not do all our jobs just a little bit - we are turning over the duties of newsletter back to the group. This issue will be our last issue so that we can focus our attention on this year's walk.

Doing the newsletter for the group has been a great sense of fun and pride for us. We have been so happy to have so many of you forward us information, write articles for the group and help us create the newsletter as it is today. We are certain that this input from you will be

needed for the folks that are going to take over doing the newsletter. You are the people who help create this masterpiece! It is through your sharing, that the information is gathered and shared with others. Please continue to do this! It is vitally important to any newsletter editor to have content and input from their readers. After all YOU ARE THE PROFESSIONALS!

We would like to encourage each and everyone of you to please come out and participate in YOUR GROUP!! As members of BUDS for the past six years we have seen the group change and grow in different directions. This is what makes support groups so great; they have the ability to adapt to the needs of the members. If you think there is an area in BUDS that could use your

group and help create - BRING IT! This is YOUR group!

Finally - we are in need of members for our Buddy Walk Committee. You DO NOT need experience. There are small jobs and big jobs available. You do not need to have a child with a disability to be on the committee. Please contact us at budsbuddywalk@comcast.net to join the committee or call us at 609-714-8565.

We thank you for your support and words of encouragement while we had this assignment and hope that you will do the same for the next editor! Thank you!

Lin and Michael Rubright (and Anna, Natasha, Rebecca, Kiley, Julia and Rachael - pictured above)

If you know of a member with Down syndrome that has been hospitalized or is going to the hospital, please contact us at 856-985-5885.

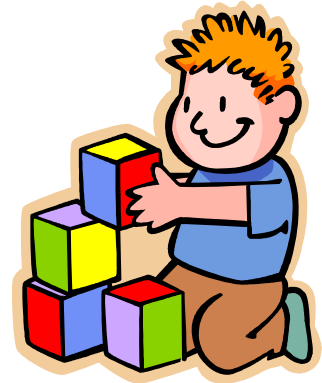
Here's What's Happening.....

BUDS at Sensory Playhouse in Turnersville —

Nancy Scully is arranging some fun for the members of BUDS to play at the Sensory Playhouse in Turnersville on Saturday, May 13th from 1:30pm to 3:30pm. The fun is open to BUDS family

members only and is limited to the first twenty-five children to register. Please be sure to wear socks for the play area. Also Nancy requests that you let her know, prior to attending, if your child has any allergies (latex, food, etc.). To RSVP for the fun call Nancy at 856-566-2487.

Hope to see you there!



BUDS 8th Annual Golf Classic



“Fore!” Time to step up and swing for the BUDS 8th Annual Golf Classic being held at Medford Village Country Club in Medford, NJ on Monday, June 12th. Bob Hennefer is organizing this year's golf classic for us. A fabulous day including 18 holes of golf, a continental

breakfast, exclusive prizes and a barbecue lunch is in store for our golfers this year. A fun time will certainly be had by those who attend.

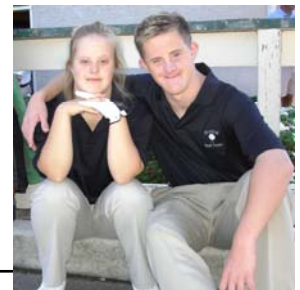
Have you shared your brochure with your family, friends, coworkers and employer?? This golf classic is one of only two BUDS fundraisers we hold all year. There are so many ways to get involved with our golf outing, besides the obvious fun of a day of golfing. You can ask your employer to sign up for one of the many sponsorship opportunities; from Golf Carts at \$25 to Gold Sponsorship at \$1,000 there is a level available to everyone at any budget!

Volunteering to help the day of the outing is a fabulous way to lend support as well! Volunteers are still needed to

make this year's golf classic a success.

Another way to get involved is to spread the word about our golf classic. This increases awareness about Down syndrome.

To volunteer to help the day of the walk, for more information or to get sponsorship brochures, please contact Bob Hennefer at 856-354-0584. Thanks to Bob for organizing this event and have a great day of golf everyone!



11th Annual BUDS Buddy Walk Needs YOU!

The winds of change are in the air for this year's BUDS Buddy Walk. The Schuitema Family and the Conolly Family have retired from the committee and are looking forward to enjoying the day from the sidelines this year. Our largest fund raising team, King Tut, is moving to Denver next week. While we wish our friends well in their new roles, we are searching for fun people to fill some fabulous shoes - on the committee and at the walk! Our annual BUDS Buddy Walk has grown to approximately 1,600 walkers. That's a lot of hot dogs, t-shirts and kids on slides! If you like to have fun and are looking for a night out (did we mention we

usually have snacks too?) please consider joining our Buddy Walk committee.

Our BUDS Buddy Walk and our Annual Golf Classic are the only two fund raisers BUDS holds to provide all of the funds for our group. These two events raise money for everything from friendraiser events, conferences, administrative costs and even the printing and postage of this newsletter! So we have a big job ahead! Our goal for this year is two fold. We'd like to cut the costs of our Buddy Walk, which will require more sponsorship, donations and discounts. We also want to raise the awareness of the Buddy

Walk with more knowledge and media coverage for the public. This means getting more people aware of our BUDS Buddy Walk and obtaining more support than ever from the community! We want to make this year's walk the huge success it has always been in the past and then some! If you have great ideas to share, or even just want to help out with some small tasks, please contact Lin Rubright at budsbuddywalk@comcast.net or call 609-714-8565. Our next committee meeting will be on Tuesday, May 9th at Paul and Maria William's home in Voorhees. It's not too late to join us!

YOUR HELP IS NEEDED!

Please consider becoming part of the Buddy Walk Committee! It is a great group to work with and the rewards are even greater! Please contact Lin or Michael Rubright if you are interested at budsbuddywalk@comcast.net The next committee meeting is on Tuesday, May 9th at 7:30pm at the William's home in Voorhees! Come join us!

Mark the date!

The 11th annual BUDS Buddy Walk will be held on Sunday, October 1, 2006!

The following Buddy Walk Committee Chairs are still open:

Equipment Coordinator
 Food Coordinator - Breakfast and Lunch
 Volunteer Coordinator
 Prize Raffle
 Mailings
 Tables



We need your help! Our 2006 Buddy Walk Committee is looking for fun and energetic people that would like to help create another fantastic Buddy Walk! NO EXPERIENCE NECESSARY! We have some big and little jobs still available.

On Raising Becca ~ By Shelly Garner

When I was asked to write this article there were many things I thought of writing about. First I thought, I'm not an expert, what do I have to offer in terms of what I know. And then I thought, well, I have lived with a child with Down Syndrome for her whole life, if I'm not an expert on my own child, who could be? I could have written on the statistics of health issues with children like my daughter. I could have written on the chances of her having this or that problem, or of when she was going to be potty trained or when she might learn to read but that would not be what raising a child like Rebecca is really all about. My daughter has Down Syndrome, that doesn't mean she is Down Syndrome, she has it, and it's only a small part of who she really is.

When she was born there were many complications. The doctor told my husband, while I was still sleeping off the effects of anaesthesia, that they were going to test for Down Syndrome. My husband told me this the next day, but there was no way **my daughter** had that. She was perfect, at least as perfect as her two sisters had been. I found out the next week that indeed, she did have DS, but she also had a serious heart defect that very likely could kill her. Now, what do you think was the most important news? The fact of DS took a big second place and that is pretty much the way it has been ever since. She has survived many close calls, extensive heart surgery, and at least six other surgeries, one in which she coded but came back to us. But in all that time, she has known she was loved beyond measure, which I am pretty sure is the most important thing in all your relationships in life.

I do believe, that you must work very hard to have a child with DS develop their full potential. And these things are not offered to you on a plate, you must look for the help you need. Becca had early childhood intervention and a marvellous interventionist who loved her and definitely wanted the best for her. We went to the Wascana Rehabilitation Centre in Regina, quite often in the first years of her life, for physical therapy and occupational therapy; we joined the Saskatchewan Association for Community Living, which sponsored us to go to seminars where we learned so much. But you also have to temper learning with relaxing and enjoying this child. Knowledge is nothing if you don't know how to use it. Becca started school at three years of age, which is normal for a child with many diagnosed disabilities. I know there were children in her class with autism and global learning delays and also others with DS.

I wanted her to have the contact with other children and also to learn how to behave in an environment where she must listen. She had remarkable teachers there, once again who loved her and wanted the best for her. But you must make sure that even though your child is loved and given good skills, that you follow your instincts as to what you know they need. In my case, I knew that Becca would go farther if she were integrated fully into a regular classroom. I had to make a decision to take her out of that school and put her into another one, which was a difficult decision but one I was very glad I made. We found in our own neighbourhood school an environment where Becca is definitely disciplined but where she has been nurtured to her full potential. They have found many computer programs that work to her advantage and she was given a very good routine, with an aide from heaven, who was with her for four years. Because Becca needed speech therapy, this aide went with her to learn how to help her on a daily basis, and Becca thrived on this environment.

Becca has had an incredible life so far. She is now 12+ years old and is in Grade 6. She plays the piano, just started taking baritone in the school band, reads very well, swims, tried guitar lessons, although stretching her fingers around the neck of a guitar and her mind around the music on the page was a little too much for her and is at least as good on a computer as most kids her age. But even more important than all this, she is a happy person, a fulfilled person, one who receives love and gives love. This doesn't mean that she isn't a pain in the butt sometimes, she fights with her

On Raising Becca ~ By Shelly Garner

brother and mouths off, like most kids in the beginning of puberty but the important thing to realize is that this kid is the same as any other. You are going to have problems, you are going to get mad, frustrated and maybe even feel like giving up sometimes. But you know what, everyone feels like that. Every parent feels like that.

We haven't finished raising this child yet, but I am proud. Very proud that I have done what I could for my girl and even more proud of her. She has worked so hard for every little thing she has accomplished. But I would have been proud of her no matter what she had done. Because she is my child and I love her and that is the only thing that is important in the end.

I have made a list of things that I consider the most important to remember.

1. Love, love, love that kid.
2. Relax, enjoy, have fun.
3. Remember, the experts don't always have every answer, and they change their minds a lot. Listen to yourself, if it feels like the right thing to do, then do it. Sometimes, you have to let an idea sit for a while and then go back to it.
4. Get involved, go to the school, talk to the teachers, talk to other parents, you are not alone and other people care too.
5. Let your child try, if they don't try they can't do it, failure is a part of life, not trying is more of a failure. Other people may tell you that it may be impossible for your child, don't listen.
6. Do not look back, do not regret, if you make a mistake, if you get mad, forgive yourself, get over it, have a nap and wake up renewed, ready to try again.
7. Love yourself, take care of yourself. If you aren't okay, then you aren't there to take care of your child. Take time off now and then, go for a walk.
8. Thank your higher power for this gift that you've received.

I personally feel that having Becca was one of the best things that ever happened in my life. I hope that if you walk this same path that you will feel that way also.

Remember:

*"It is difficult to say what is impossible,
for the dream of yesterday is the hope of today and the reality of tomorrow."*

- Unknown

"To become what we are capable of becoming is the only end in life."

- Robert Louis Stevenson

"If you think small, then your limits have already been established."

- World Peace

Shelly Garner has resided in Moose Jaw most of her life. She is married to Brian and has four children, two living at home, two grandchildren, two dogs, a cat and four fish tanks. She is a certified reflexologist, works as an office assistant for a local specialist, is treasurer for the Moose Jaw Branch of the Saskatchewan Association for Community Living and belongs to the Saskatchewan Family Network, a grassroots alliance of parents whose children have differing abilities. She is an avid gardener and preserver, who loves to share with family and friends.

*Shelly is a regular contributor to **Gwen's Healing Garden Newsletter** and writes gardening articles. She may be contacted at (306) 693-0571 or e-mail: b.garner@shaw.ca (Reprinted with permission)*

**Teen and
Young Adult
Group**

If you haven't attended an event or sent in your registration form to be included on the Teen & Young Adult mailing list, you can still do so by emailing threehens@aol.com or calling Nancy Hennefer at (856) 354-0584.

Teens For Teens ~ By Jillian Hagner

Last April I started a program to merge the BUDS Young Adult group and the St. Andrews Youth Group, that of which I am an active member. Mrs. Sue Orthey and Mrs. Nancy Hennefer from BUDS were instrumental in helping me organize these plans. We planned four activities over the course of the year to join the two groups of teens.

In April we started things off with a mini-golf outing at Pleasant Valley Mini-Golf. After taking a break for the summer the two groups reconvened in October for a frightfully fun Halloween party. We had an excellent turnout of approximately 65 teens dressed in costumes and prizes were awarded for originality. Following that we

held a karaoke party in January. The latter two events were held in the auditorium at St. Andrews Church and BUDS gener-

ously provided the snacks. Our last event for this year will be a dinner and movie night in April. The two teen groups gelled nicely together forming friendships over time. We all learned a great deal from each other. Both groups benefited from the activities. The BUDS teens experienced a night of fun without their parents' watchful eye. St. Andrews teens spent time sharing common interest with the BUDS teens like music, hobbies and dancing. Good times and cherished friendships are forged by teens reaching out to teens. We plan on continuing "Teens For Teens" next year.



held in the auditorium at St. Andrews Church and BUDS gener-



Minigolf Fun in the Teens for Teens Group



Letter to the Editor ~ by Shelly Garner

(Note from Lin Rubright: I usually don't put in more than one article from a writer in an effort to keep the newsletter flow loose and not any particular person's perspective. However in this time of heated debate about genetic testing and the quality of life for people who have Down syndrome, I was compelled to include this "Letter to the Editor" of Shelly's local paper. Ms. Garner resides in Canada and is a parent of Rebecca, who has Down syndrome. Ms. Garner expresses well what so many of us feel at this time of genetic testing.)

Nov. 5, 2005

To the editor:

I attended the Canadian Association for Community Living Annual Conference in Saskatoon on November 2-4, 2005. I love to attend these conferences, not just for information but also to re-connect with others whose children have an intellectual disability. There were some wonderful things happening at this conference and one of the best in my opinion was seeing a self-advocate, a person with an intellectual disability, who had not been able to get an education in Saskatchewan because his parents were told he was uneducable, receive a medal from Lt. Gov. Lynda Haverstock, for tireless work and achievements in the field of advocating for people who have intellectual disabilities. This man was Shane Haddad from Regina.

There were many topics of discussion happening and I chose to be involved with the topic of bio-ethics, in particular genetic testing. Genetic testing is done for the following reasons, to assist parents in planning or to decide whether to terminate the pregnancy. There are no therapeutic interventions presently available. There is so much to debate in this area but I would like to share some of my thoughts and feelings with you.

I have a daughter, Rebecca, who has Down syndrome. I would like to think that my daughter has a lot of value, as we all would like to think our children have value. I believe that many people have been shown that Rebecca has ability and I know that she brightens my day and the day of many others who are involved with her, both at home and at Empire Community School, where she attends daily.

I also know that the lives of many people with Down syndrome are being ended on a daily basis due to genetic testing. 40-60% of people who find out they are having a child with this and other disabilities are aborting them.

There is a serious problem with this type of testing. When does it end? When are they going to start saying, well this child has a gene for diabetes so we don't want it to end up suffering, we won't let this child live, this child has a gene for schizophrenia, he has to go, and so on and so forth.

My child doesn't suffer, she has a great life, yes sometimes she is teased, sometimes her days aren't full of people phoning to say hey, but guess what, my other children all went through the same thing.

My daughter's life has value and I for one, am very glad I didn't have the opportunity to decide whether I wanted her to live or die. I'm not sure I would have made the right choice and that is what the problem is. No one knows what their children will be like; it is a mystery until it unfolds. This is life and sometimes the roll of the dice is different from what your expectations may be.

The serious question is, do we want a uniform society. One in which there is no diversity. One in which we have to fit into the mold to be able to be recognized as a citizen with rights. I don't think so. If that were the case than most of us would be out on our ear.

We have to start thinking of disability in a different way. Grandpa in a wheelchair is disabled, after a long, productive life. I am disabled with a hearing defect, my friend with a lung disease is disabled, another relative with depression is disabled. Do we realize how much of the population we are talking about here and how many of us are affected in some way by a disability? It's not disability, it is differing ability and we all cope.

I want to be able to say that I and my children live in a country where everyone is valued, regardless of ability, where we can work, save and live comfortably and safely. Isn't that what we all want in the end?

Shelly Garner
Moose Jaw, SK

THE BEATITUDES - For Friends of Exceptional Children

Blessed are you who take time to listen to difficult speech:
For you help us to know that if we persevere,
We can be understood.

Blessed are you who walk with us in public places,
And ignore the stares of strangers,
For in your companionship,
We find havens of peace.

Blessed are you who never bid us to "hurry up",
And more blessed are you
Who do not snatch tasks from our hands to do them for us,
For often we need time rather than help.

Blessed are you who stand beside us
As we enter new and untried ventures,
For our failures will be outweighed
By the times we surprise ourselves and you.

Blessed are you who ask for our help,
For our greatest need is to be needed.

Blessed are you when you assure us,
That the one thing that makes us individuals
Is not in our peculiar muscles,
Nor in our wounded nervous systems,
Nor in our difficulties in learning,
Nor any exterior difference.
But is in our inner, personal, individual self
Which no affirmity can diminish or erase.

Author Unknown

Collingswood Special Needs Family Support

Dianne Malley is a BUDS member, as well as a member of the Collingswood Special Needs Family Support Group. This group is a division of the Collingswood PTA whose focus is to *"understand and navigate the road of Special*

Education". Diane wanted to share the many activities the group hosts, such as their May 4th Advanced Advocacy Strategies: What Every Parent Should Know and their June 10th Family picnic. Meetings are generally held at the

Collingswood Community Center. Professional Development Hours are available for most workshops, so share this info with your school professionals. For more information you can contact Dianne Malley at 1-856-858-5675.

Anna Foundation For Inclusive Education

The Anna Foundation For Inclusive Education is seeking "differently abled" students that are in an inclusive education setting who would benefit from one on one after school or summer tutoring. The students do not have to be in a fully inclusive

program, they can be partially included to qualify. In addition, we ask that you check our website for our Toner For Tutoring program (www.affie.org). There is a list of cartridges that we collect for recycling to help fund

our tutoring program. Please share this list with your family, friends, employer, etc. We will happily make pick up arrangement to collect your used cartridges. Thank you.



Hennefers Begin Golf For Life Program!

We are very proud to announce that the Hennefer family has begun the Golf For Life Program with the National Down Syndrome Congress! The Golf For Life Program is a golf instruction program provided exclusively for individuals with Down syndrome. It is being offered as a

pilot program by the Philadelphia Section of the Professional Golfers' Association of America (PGA) through collaboration with the NDSC. While the program is being officially kicked off at the NDSC conference in Atlanta in July of 2006, the Hennefers have already started with a Golf Clinic in

Voorhees on Saturday, June 10th. For more information contact Nancy and Bob at golforlife@comcast.net or call 856-354-0584. Thanks Hennefer Family and good luck!



Upcoming Events

From Span (Statewide Parent Advocacy Network). Check out their website at www.spannj.org.

APRIL 2006

April 28, 29, 30, May 1, 2006: Washington, DC Metro Area, Infancy and Early Childhood Training Course. Taught by Stanley I. Greenspan, M.D. and Serena Wieder, Ph.D. Brochure and registration materials available in January, 2006. For more information call 301-320-6360 or visit <http://www.stanleygreenspan.com/>.

MAY 2006

May 6, 8:30-4, Ramada National Conference Center, East Windsor. Annual Conference of the NJ Inclusive Child Care Project. Contact Denise Bouyer at 973-642-8100 x 112 or go to www.spannj.org for more information.

May 8, 7-8:30 pm, Don Imus-WFAN Pediatric Center for Tomorrow's Children, Room PC241, Hackensack University Medical Center, Autism and Sibling Relations. Presented by Alpine Learning Group. Info at <http://www.alpinelearninggroup.org/index.html>.

JUNE 2006

June 28-29, Montgomery High School (near Princeton), Summer Inclusion Conference 2006 "The Keys to Inclusion: Unlocking the Doors for Children with Mild to Significant Disabilities, NJ Coalition for Inclusive Education. Contact 732-613-0400 or njcie@comcast.org.

JULY 2006

July 12-15, Orlando, Florida. 2006 National Training Institutes of the National TA Center for Children's Mental Health. For more information, go to http://gucchd.georgetown.edu/programs/ta_center/index.html. Alice Hunnicutt will attend.

NOVEMBER 2006

November 10-12, ICDL (The Interdisciplinary Council on Developmental and Learning Disorders) 10th Annual Conference.

THIS LIST PROVIDED COURTESY OF SPAN - ACTIVITIES ARE NOT ALL SPAN ACTIVITIES

Congratulations to the BUDS basketball team!

Three years ago when the team was formed, little did we know that the team would go on to win a Special Olympics of New Jersey (SONJ) state championship. However, that's exactly what the BUDS team did during the March 18th and 19th SONJ state basketball competition in Wildwood, NJ. BUDS played four games during the two-day state tournament and won all four games to clinch the Division VII state title. WAY TO GO TEAM!!

Team Picture:

Front Row l to r: Samantha Orthey, Michael DeLaurentis, Michelle Dobry, Jennifer McKeown, Henry Schuitema

Middle Row l to r: Brad Hennefer, David Praiss, Kristin Campbell, Peter Brodzinski

Back Row l to r: Coaches Bob Hennefer, Henry Schuitema, Ray Dobry and Rob Orthey (missing Coach Bill Lessig and Lauren Minich)



Websites

www.kidstogether.org
www.ndss.org
www.ndscenter.org
www.nads.org
www.tash.org
www.spannj.org
www.trisomy21online.com
www.downsed.org
www.21down.org
www.kiids.info
www.njea.org
www.specialolympics.org & www.sonj.org

Inclusive Websites

www.inclusion.org
www.inclusion.com
www.uni.edu/coe/inclusion
www.inclusive-education.com
www.tash.org/education

Helpful Products?

www.superduperinc.com
www.disabilitytraining.com
www.adcohearing.com
www.loveandlearning.com
www.enablemart.com



B.U.D.S.

Bringing Up Down Syndrome

P.O. Box 1085
Marlton, NJ 08053

Phone: 856-985-5885

Email:
buds.newsletter@
comcast.net

We're on the web!
www.budssj.org

Is Down syndrome new to you or someone you know? Call our Outreach Coordinator, Kathy Beckett at 1-856-797-7922.

Postcards will NO longer be mailed for each event - please mark your calendar!

The information contained in this newsletter is provided as information for our readers, and is not necessarily the opinion of the editor, or endorsed by the support group.

Know Your Officers

Co-Chairs: Sue Orthey (email REGAN65@aol.com) and Joanne McKeown (email bobmckeown@earthlink.com)
Secretary: Jane Conolly (email jconolly62@comcast.net)
Treasurer: Nancy Hennefer (email THREEHENS@aol.com)

It's time to vote for officers soon!

Are you ready to take the lead??

We are looking for people interested in becoming officers!

We need interested candidates to email Sue Orthey with the position you are interested in - Chairperson, Vice Chair, Secretary & Treasurer.

Look for officer voting in your mail some time in June!

BUDS UPCOMING EVENTS

Tuesday, May 9th - Buddy Walk Meeting in Voorhees

Saturday, May 13th - Sensory Playhouse in Turnersville

Monday, June 12th - 8th Annual Golf Classic at Medford Village Country Club in Medford