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THE EVOLUTION OF BRINGING UP DOWN SYNDROME

Most of you know that Bringing Up Down Syndrome (BUDS) is the Southern New Jersey affiliate group of both the National Down Syndrome Congress (NDSC) and National Down Syndrome Society (NDSS). What many of you may not know is some of the history of BUDS and how we are continuing to evolve.

BUDS was started in 1984 by a small group of parents who, back then, spent much of their time advocating for basic rights such as inclusion in education. We are very fortunate to have four of the original co-founders (Paul Williams, Maria Williams, Joanne McKeown and Bob McKeown) still involved in the group, which has grown through the years, and now serves families primarily in the Camden, Burlington and Gloucester county areas.

What is so unique about BUDS is that our programs have continued to evolve as our world has changed and as our family members have grown older. For instance, new parent outreach now includes sending a book collection directly from Amazon.com. Most of the books, nor Amazon, did not even exist when we first began BUDS. While many parent groups do a fabulous job of new parent outreach, educational advocacy, and fun social events for young children, it is often very challenging to continue to provide quality programs as our family members graduate and transition into adulthood.

Over the years, we have organized our social groups into teams called BUDS Kids, BUDS Tweens, BUDS Teen & Young Adults and our newly formed "BUDS Over 21." Each team has a leader that coordinates a calendar of events that is age appropriate. We've also formed alliances with community partners such as the Cherry Hill Health & Racquet Club, Rowan University and Velocity Sports Performance (www.velocitysp.com/cherryhill).

When our children started aging out of school and community sports programs, we started our own Special Olympics teams exclusively for BUDS members. When our young adults started to encounter weight management issues, we started our own weekly fitness program through Velocity Sports Performance. When our students graduated but still wanted continuing education, we offered tutoring programs. The point is that BUDS continues to evolve as our demographics change.

As part of that evolution, we have recently amended our Bylaws (available at www.bringingupdownsyndrome.org), we have added new members to our Board of Trustees, our mailing address has changed, and we have formed new committees. In addition, we also have a new brochure that may be provided to new families, sponsors, the medical community, educators and others who are interested in our organization.

In summary, we are a dedicated group of parents, young and "older" who have come together with the common goal of doing everything we possibly can to enrich the lives of our family members who happen to have an extra chromosome. Some of us have known each other for over 25 years. However, we are still amazed each and every day at the many accomplishments of our "BUDS" who continue to blossom into young adults, many of whom are employed and lead healthy and active lives with a social calendar that is often busier than our own. We hope you will join us on this journey by joining one of our committees. We've highlighted the activities that our committees are responsible for, and we look forward to welcoming new faces and ideas as we continue to evolve and move forward.

Sincerely,

*Bringing Up Down Syndrome
Board of Trustees*

ABOUT OUR COMMITTEES

We are organized into the following committees, and we are always in need of new volunteers.

We've outlined what each committee does, and we have provided the chairperson's name. If you want to meet and network with other families, one of the best ways to do that is to join one of the committees. You can do as much or as little as you like, but the friendships that you will make are the true benefit of working on the committees.

1. **Buddy Walk Committee** Chairperson, Paul Williams
2. **Social Programs & Support Committee** Chairperson, Nancy Hennefer
3. **Advocacy & Outreach Committee** Chairperson, Joanne McKeown
4. **Athletics & Physical Fitness Committee** Chairperson, Bob Hennefer
5. **Education, Health & Wellness Committee** Chairperson, Sue Orthey
6. **Public Awareness Committee** Chairperson, Kim Brooks

The Buddy Walk Committee - Chairperson, Paul Williams

The Buddy Walk committee is responsible for coordinating the annual Buddy Walk. Without the hard work of the Buddy Walk committee, we simply would not be able to offer our programs. The duties of the Buddy Walk committee will include, but are not exclusive of:

1. Prepare and present to the Board, for approval, a budget for the Buddy Walk.
2. Execute agreements with vendors for the Buddy Walk, as budgeted.
3. Prepare, review and approve Buddy Walk media brochures.
4. Perform other duties as may be required to carry out the coordination of the Buddy Walk.

Social Programs & Support Committee - Chairperson, Nancy Hennefer

1. Provide long-term strategic direction, leadership and oversight of social programs and support activities.
2. Oversee social group programs, calendars of events, and budgeting to ensure that there is continuity of activities for all age groups including young children, teenagers, and young adults. Liaison with social group coordinators who may or may not be Trustees or Officers.
3. Provide support to families by mentoring, offering parent contacts, sending get well gifts, and providing relevant information or resources, as needed.
4. There are five subcommittees with "coordinators" as follows:

- BUDS "Kids" Kim Brooks
- BUDS "Tweeners" Nancy Scully
- BUDS "Teens" Toni Slowinski & Anitra DiOrio
- BUDS "Teens & Young Adults" Nancy Hennefer
- BUDS "Over 21" Jan Brodzinski

Advocacy & Outreach Committee (Chairperson, Joanne McKeown)

1. Provide long-term strategic direction and leadership of advocacy and outreach activities.
2. Be a knowledgeable advocacy resource to parents and liaison with county, state and national organizations as needed.
3. Oversee outreach to families, hospitals, schools, obstetricians, pediatricians, genetic counselors and other interested parties.

Athletics & Physical Fitness Committee (Chairperson, Bob Hennefer)

1. Provide long-term strategic direction and leadership of athletic and physical fitness programs.
2. Oversee and monitor Special Olympics teams that are financially supported by the Corporation.
3. Oversee other year-round physical fitness training programs.

Education, Health & Wellness Committee (Chairperson, Sue Orthey)

1. Provide long-term strategic direction and leadership of education, health and wellness activities.
2. Provide the newsletter editor with information on relevant conferences, books, magazines, periodicals and articles of interest; coordinate conference reimbursement; liaison with educational speakers, as needed.
3. Oversee programs such as tutoring, nutrition education, and other health and wellness programs.

Public Awareness Committee (Chairperson, Kim Brooks)

1. Provide long-term strategic direction and leadership of public awareness and media relations activities.
2. Oversee public awareness activities, including preparing newsletters, brochures, and other publications.
3. Monitor website content, social media content (e.g. Facebook) or other means of publicity (e.g. newspapers, magazines, radio, TV).

ADVOCACY & OUTREACH COMMITTEE NEWS

One of our goals for 2013 is to increase our advocacy and outreach efforts, particularly to new families and the medical community. We have NDSC, NDSS, and "Downsyndrome pregnancy.org" publications as well as our own brochures if you would like to provide them to specific families, physicians or educators. If you would like to join our committee, please contact Joanne McKeown at (856) 256-9412.

ATHLETICS & PHYSICAL FITNESS COMMITTEE NEWS

We realize the importance of life-long physical fitness. We sponsor several Special Olympics of New Jersey athletic teams and have partnered with Velocity Sports Performance and the Cherry Hill Health & Racquet Club. The Velocity Sports program for our Special Olympics athletes will end on June 23, and we will take the summer off. We will resume training again on September 22 to get ready for fall and winter competition. For more information, feel free to contact Bob Hennefer at (856) 354-0584.



BUDDY WALK COMMITTEE NEWS

▶ Walk Committee Meeting Dates

Be sure to save the date for this year's 17th Annual Buddy Walk on Sunday, October 7th at Washington Lake Park, Turnersville, NJ. We are in need of additional volunteers for this Buddy Walk and **welcome you to attend one of our upcoming Buddy Walk committee meetings.** The upcoming meeting dates are August 27th and September 24th. If you are able to attend, please RSVP to Paul Williams at williamspg@verizon.net.

▶ Buddy Walk Corporate Sponsors

The Buddy Walk is our primary fundraiser that supports our programs. Each year, we are grateful for all of our corporate sponsors, but like most nonprofit organizations, raising additional funds from corporate sponsors is challenging in today's economic environment. Here is how YOU CAN HELP! To show your appreciation for our year-round programs, **we would greatly appreciate it if each family could provide our corporate sponsor donation forms to your employer or other potential sponsors.** We've included the corporate sponsor forms in this newsletter so they are easily accessible to you. They can also be downloaded from our website at www.bringingupdownsyndrome.org. This is one way that you can truly help us, especially if you participate and value our programs.

▶ Buddy Walk Celebration Gallery

Each year at our Buddy Walk, we have a celebration gallery where we display personal stories about our BUDS families. There are no milestones too small or too large to share with our community. We'd love to hear about your family member who has Down syndrome, see their pictures, and learn more about their personal journey. **We'd like to encourage you to please submit a celebration gallery story.** Included in this newsletter is the submission form. This is also another way that you can truly help us, by sharing your family's journey. The form can also be downloaded from our website. Please submit the form as early as possible to Kathi Pinto at njpintos@comcast.net. All submissions will be entered into a drawing for a special gift basket at the Buddy Walk.

SOCIAL PROGRAMS & SUPPORT COMMITTEE NEWS

Social Programs Planning Meeting

You are all probably familiar with our various social programs. The calendar of events is on our website. This is just a reminder that most of the programs do not meet during July and August, so we hope to see you in June before we wind down for the summer. We are actively planning our calendar for 2013 and would welcome your input. **If you would like to be included in our planning meeting, please contact Nancy Hennefer at nhennefer@comcast.net.** We are always in need of additional volunteers to help coordinate and plan our events.

Family Support

If you become aware of new families who have a baby with Down syndrome, please let us know. We typically send a book assortment from Amazon.com of the most recent books on Down syndrome. We would also like to know if your child is having surgery or is hospitalized so we can send a special get well surprise. Please e:mail Nancy Hennefer at nhennefer@comcast.net if you are aware of families in these situations.

PUBLIC AWARENESS COMMITTEE NEWS

Join Our Facebook Group

We encourage our children to be self-advocates, to follow their dreams and set high standards for themselves. We work tirelessly to promote positive public awareness that individuals with disabilities can be valuable, contributing members of society. If you would like to share your positive stories with us, please join our Facebook group at "BUDS-Bringing Up Down Syndrome SJ."

Down Syndrome Awareness Day at the Philadelphia Zoo

Please save the date for Down Syndrome Awareness Day at the Philadelphia Zoo, which will be on Sunday, September 16th. We are one of the sponsors for this event, and you may attend at no charge as long as you register and request reimbursement. More details will follow as we get closer to the event.

Newsletter Articles & Personal Interest Stories

We receive the most positive feedback on newsletter articles about our BUDS families. If you would like to write an article for us about your family's journey, we would greatly appreciate it. Please submit your personal story or other article that you think may be of interest to Kim Brooks at kim@himandkim.com

EDUCATION, HEALTH & WELLNESS COMMITTEE NEWS

National Down Syndrome Congress (NDSC)

40th Annual Convention, Washington, D.C. July 20 – 22, 2012

If you have never gone to a NDSC convention, this may be the year to consider it. The convention rotates through the U.S. at various North, South, East and West locations. This year it is on the East Coast, conveniently located in Washington D.C. It won't be back on the East Coast again until 2016. There is a "Kids Camp," "Brothers & Sisters Conference," "Youth & Adults with DS Conference" and then the general convention for parents. Online registration opened up on March 5th at www.ndscenter.org. BUDS will reimburse you for the registration fee only (not travel costs). Mail a copy of your online registration receipt to Nancy Hennefer, 1115 Yardley Rd., Cherry Hill, NJ 08034 to request reimbursement (or email copy) to nhennefer@comcast.net

SAVE THE DATE









SUNDAY OCTOBER 7, 2012

Registration: 10 a.m. | Walk 11 a.m.
Rain or Shine
Washington Lake Park, Turnersville

Join us for a one mile walk around the park. Bring your friends and family. Meet new people & enjoy...

Raffles, Music and Games!

**Walk as an Individual or Organize a Team.
Register and dontae online.**

Stay up-to-date by going to www.BringingUpDownSyndrome.org for early registration sign-up.