

**Adult Down Syndrome Center
Advocate Medical Group
Lutheran General Hospital**

November 17, 2008

Brian Chicoine, MD

Fitness Team

Come join us at the race that started the ADSC Fitness team.

Sunday November 23
Lincolnwood Turkey Trot

Several of us are doing the 5 K walk/run (3.1 miles)

<http://www.lincolnwoodil.org/recreationturkeytrot.cfm>

2008 Lincolnwood Turkey Trot

DATE: Sunday, November 23, 2008

TIME: 8:45am - 5K / 10K Run - Champion Chip Timed Event

9:00am - 5K Walk

10:30am - Drumstick Dash

PLACE: Proesel Park Shelter

Morse and Kostner Avenues, Lincolnwood

RACE: 5K and 10K Run, 5K Fitness Walk and a Drumstick Dash for children 10 & Under

AGE DIVISIONS: 9 and under, 10-14, 15-19, 20-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80 & up.

AWARDS: Long sleeve T-shirts guaranteed for all PRE-REGISTERED runners and walkers. Turkey trophies awarded for 1st, 2nd, and 3rd place in each age division, male and female, in each race. Awards given to top male/female Lincolnwood finishers in each race. A turkey and special award given to each male and female overall winner in each race. The 5K walk is non-competitive and all walkers will receive a participation award.

REFRESHMENTS: Free for all participants and volunteers.

ENTRY FEES:

\$22.50 OnLine Registration (www.lincolnwoodil.org)

\$29 Pre-Race Registration (Mail or Drop Off)

\$33 Race Day Registration

\$12 Drumstick Dash Pre-Race Day Registration

\$14 Drumstick Dash Race Day Registration

** CARA Discount (\$2.00)

** Lincolnwood Resident, 5K/10K Discount (\$2.00)

** Lincolnwood Resident, Drumstick Dash Discount (\$1.00)

We had a great time at the American Heart Association Walk at Harper College in Palatine on Sept 28th. Our team photo is below.



Chicago Marathon

Thank you for all who donated to the Adult Down Syndrome Center Chicago Marathon/Fitness Team Fundraising effort. We had 4 people participate this year. Thank you to Dr. Robert Moss (Advocate Medical Group Geriatrics) and Dr. Michael Fisher (Family Medicine) who ran and completed the marathon and generously helped raise funds for the Center. Thank you also to Dr. Erin Dominiak of the Center. Erin and I walked part of the marathon. Erin had a “bug” leading up to the marathon that cut short her training. I had hurt my knee in July running up a hill and finally had to admit in mid-Sept that it wasn’t likely I could run the marathon. We enjoyed a walk through the city and stopped at the water station where my youngest daughter, Laura, was passing out water with her high school cross country team.

The event was a disappointment from a personal athletic standpoint (particularly after having run 1100 miles in the year between the 2007 and 2008 marathons in preparation for the event), However, it was a pleasure to once again to be part of such an incredible event with such a wonderful

group of people. Even more amazing was the incredible generosity of our supporters. Even in these tough economic times we raised nearly \$60,000.00. Thank you for your generosity. The donations are very much appreciated and needed. We only receive reimbursement of \$1 for every \$3 that we bill (due to the reimbursement rates of Medicare and Medicaid). In addition, some of the services we provide are not reimbursed at all. Again, thank you for helping make the ADSC possible.

A few years ago I had the opportunity to play a very tiny role in the passage of the ‘Prenatally and Postnatally Diagnosis Conditions Awareness Act’ (see below). I was one of several people given the opportunity to present before a Senate Sub-Committee in Washington DC. Sen. Brownback’s (KS) staff asked me to present about adults with Down syndrome. He wanted to get on the record that adults with DS were living longer, achieving in ways not previously seen, and participating in society in so many wonderful ways.

The case was presented over time that this type of information was not being distributed, particularly in the medical community with regards to families receiving the diagnosis of Down syndrome (both prenatally and postnatally). The result was the passage of the Kennedy-Brownback Prenatally and Postnatally Diagnosis Conditions Awareness Act (see below).

The Down Syndrome Community Celebrates an Important Victory
Congress Passes the Kennedy-Brownback Prenatally and Postnatally Diagnosed
Conditions Awareness Act

New York, NY (September 26, 2008). After three years of advocacy, the U.S. Senate and the U.S. House of Representatives passed S. 1810, the Prenatally and Postnatally Diagnosis Conditions Awareness Act, during this last week before Congress adjourns . The legislation has been an extremely high priority for the National Down Syndrome Society (NDSS) and the National Down Syndrome Congress (NDSC). These organizations and individuals with Down syndrome and their families across the country are convinced there is a need for physicians and other health professionals to provide parents who receive a prenatal or postnatal diagnosis with updated, evidenced-based information about Down syndrome.

U.S. Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS), original co-sponsors of the bill, came together to pass S. 1810. The bill passed the Senate by

unanimous consent on September 23rd and passed the House by a voice vote on September 25th.

The Prenatally and Postnatally Diagnosed Conditions Awareness Act ensures that pregnant women receiving a positive prenatal test result and parents receiving a postnatal diagnosis will be more likely to receive up-to-date, scientific information about life expectancy, clinical course, intellectual and functional development, and prenatal and postnatal treatment options. It offers referrals to support services such as hotlines, Web sites, information clearinghouses, adoption registries, and parent support networks and programs specific to Down syndrome and other prenatally diagnosed conditions. The information that is all too often being provided in these situations is out-dated and inaccurate. The treatment options, functional development, opportunities and accomplishments of individuals with Down syndrome have improved dramatically over the years, yet decades old stereotypes still persist. It is critically important for healthcare professionals, families and society to update their knowledge and their perceptions about individuals with Down syndrome.

NDSS, NDSC and affiliate groups across the country, have worked for almost three years to bring the bill to passage. J. David Hoppe, NDSS Governmental Affairs Committee Chair, worked tirelessly with Members of Congress to ensure the bill would be considered despite competing time demands in Congress. “With one small eight-page statute we have the power to brighten the future for people with Down syndrome and their families, by breaking stereotypes and dispelling myths”, states Hoppe.

NDSC and NDSS and appreciate the hard work of the Members of Congress who championed the bill in the Senate and the House of Representatives—Senators Edward Kennedy and Sam Brownback, Congressmen James Sensenbrenner and Tim Ryan.

Other members of Congress who provided invaluable assistance and support- Senator Harry Reid, Speaker Nancy Pelosi, Majority Leader Steny Hoyer, Senator Mitch McConnell, Congressman James Clyburn, Minority Leader John Boehner, Congressman Roy Blunt, Congressman John Dingell, Congressman Joe Barton, Senator Jon Kyl, Congressman Pete Sessions and Congresswoman Cathy McMorris Rodgers.

NDSS and NDSC would like to thank the members of the Trisomy 18 Foundation and their leadership who were diligent and stalwart supporters in the effort to pass the bill.

NDSC and NDSS would also like to thank their affiliates and the thousands of individuals with Down syndrome, parents, families and friends who have worked tirelessly during the three-year effort to pass the legislation.

About NDSS

The National Down Syndrome Society is a nonprofit organization with more than 250 affiliates nationwide representing the more than 400,000 Americans who have this genetic condition. NDSS is committed to being the national leader in supporting and enhancing the quality of life, and realizing the potential of all people with Down

syndrome. We demonstrate this commitment through our education, research and advocacy initiatives that benefit people with Down syndrome and their families. To learn more visit our new website www.ndss.org.

About NDSC

The National Down Syndrome Congress is America's oldest national organization of individuals with Down syndrome, their families, friends and the professionals who work with them. NDSC works to promote equal rights and opportunities for individuals with Down syndrome through advocacy, information and education. The NDSC also hosts the world's largest annual gathering of teens and adults with Down syndrome, as well as parents and professionals. For more information, please visit www.ndscenter.org.