

CSD NEWS

Volume 4, Fall 2006

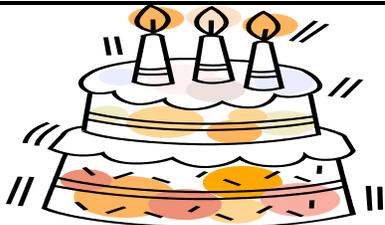
A publication from the staff of the
Center for Skeletal Dysplasias at Hospital for Special Surgery



NEW FACES, NEW BEGINNINGS

We are very excited to have a new member to the CSD staff. Frances Baratta-Ziska, PT, has now joined us as of August 2006. She will be available to see patients during their CSD appointments for assessment as well as make recommendations for therapeutic exercises and adaptive equipment. We now have a full complement of disciplines at CSD:

Geneticist.....*Jessica Davis, MD*
Genetic Counselor.....*Erin Carter, MS*
Nurse.....*Anne Schotman, RN*
Nutritionist.....*Deborah McInerney, MS, RD, CDN*
Orthopedic Surgeon.....*Cathleen Raggio, MD*
Physical Therapist.....*Frances Baratta-Ziska, PT*
Social Worker.....*Lorraine Montuori, LCSW*
Volunteer Extraordinaire.....*Norm Elia*



THREE YEARS AND GOING STRONG

This summer CSD achieved our 3rd anniversary as the center of excellence in the Northeast specializing in the diagnosis & treatment of people with skeletal Dysplasias. The first three years have happened quickly, but we are

very proud of all the progress that has been achieved & can only imagine what progress will occur in the future. Some of the CSD achievements to date are:

- Obtaining orthopedic surgical intervention for some patients (adults & children) who required spine or hip surgeries.
- MRI CSF Flow Study capability at HSS.
- CSD Clinical Research Registry
- Bisphosphonate Research studies
- Longitudinal patient satisfaction trending
- Special Events (social, educational)
- Mentoring Program

Mentoring Program

The CSD Mentoring Program had its inauguration this summer. It was a very successful and exciting time for all participants. Danny Fava spent the summer working in the HSS Technology Transfer Department. A story in the HSS monthly, ECHO, featured a story about the program and Danny's participation. In ECHO, Danny spoke about why he was interested in the CSD Mentoring Program. *"I had such a positive experience as a patient at HSS that I wanted to work here and be part of*

HSS," said Danny Fava, the mentoring program's first placement. (ECHO, Vol. 8, Issue, 9, September 2006.) High school students, ages 15 and older, who are CSD patients can apply for internships during the school year or summer. Any interest or questions? Please contact Lorraine at 212.606.1031.



Hospital for Special Surgery has updated the look, as well as the content, of its website (www.hss.edu). Look for CSD under the heading Departments and Services to see how we have also broadened our content and information.



Erin and Lorraine traveled non-stop from LaGuardia to Milwaukee to participate in this year's national LPA Conference. In addition to seeing some of CSD families & participating in workshops (not to mention how much we enjoyed the fashion show!!), Lorraine led her workshop "What It's Like Being Me" with children, teen-agers and

siblings. We are looking forward to Seattle next summer.



If you have had a recent change in address or wish to be removed from the CSD mailing list entirely, please contact us at 212.774-7332 or at csd@hss.edu.



THAT'S ALL FOLKS !!!

This concludes our latest newsletter. We are planning to send newsletters out twice a year to our patients and their families. However, just like with everything else, we would like your input. Do you have some thoughts, a story, some resources, or other useful information that you would like to let others know about? If so, please send them along to us. You can mail us at:

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