

CSD NEWS

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 on the CSD staff. Deborah McInerney, MS, RD, CDN will now be seeing CSD patients for dietary and nutritional assessment. Nutrition can have a big impact on feeling well, even with chronic health issues, and Deborah has a lot of good information to pass along. Make sure you see her at your next CSD appointment.



CSD MENTORING PROGRAM

In our last newsletter, we announced the creation of the CSD Mentoring Program. This specialized program is available to teen-agers who are CSD patients. Due to the support of the Hodgson Family, we are now able to offer a mentoring program for CSD patients to help them develop work skills that are compatible with individual talents and abilities as well as to help with career planning. Internships are available at Hospital for Special Surgery for CSD patients who are high school students. 2 types of internships are available:

- Academic year—8 hours/week for 25 weeks.
- Summer—25 hours/week for 8 weeks

Travel expenses, up to \$ 100/month will be reimbursed and participant will receive a stipend of \$ 2000 upon successful completion of the internship. Mentoring program will also be available to help assist with application fees for college or specialized program/trade school. Assistance with exploration of funding sources for higher education is also incorporated into this unique CSD program.

So, for anyone interested, here is how to apply:

- The applicant must submit a letter to the CSD staff telling us why he or she would like to be a part of this program.
- Applicant must submit 2 letters of recommendation: one from staff of the school that the applicant attends and one from a personal (not a relative) contact.

Once an applicant is approved, we will meet with the student and family to discuss the specifics of the internship site and the program. Students may have more than one internship

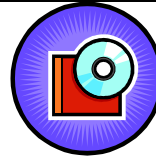
over time; however, once the student has graduated high school, he or she will no longer be eligible to participate in the program. (If the student will be graduating during the course of an internship, he or she will be able to continue with the current internship.) *For summer 2006, we are able to expand the summer program and offer internships to CSD patients who are on their summer break from college.*

We have several HSS departments and physicians who are ready to welcome students and get those internships going. We're ready to begin; anyone interested should send a letter of application promptly.



On September 26, 2005 CSD hosted a memorable evening honoring Betty Adelson's 2 new books, *The Lives of Dwarfs: Their Journey From Public Curiosity Toward Social Liberation* and *Dwarfism: Medical And Psychosocial Aspects Of Profound Short Stature* at the Menschel Conference Center at Hospital for Special Surgery. This well attended evening started with some moving personal reflections by Julie Rotta. After Julie's opening remarks, Betty presented a centuries long historical perspective on the lives of little people. After the presentation, the

forum was opened up for questions. As a result of some questions, some very interesting discussions occurred around the topics of use of language (dwarf vs. little person, specific type of dysplasia vs. indicating having a skeletal dysplasia) as well as the theme of being a person of color *and* having a skeletal dysplasia.



WE ARE ONLINE !!!!!

Ever have trouble answering questions about what CSD is or where Hospital for Special Surgery is? Here's a simple solution. Tell your family and friends to check us out online. Thanks to our friends at Hedley Media Inc., CSD has its own very personal DVD that lets everyone know who we are and what we do, while providing education about skeletal dysplasias.

Check out the HSS website to find out about CSD and view this distinctive DVD. It is located at www.hss.edu and CSD is listed under Departments and Services.



CALLING ALL ARTISTS & POETS

We know you are a creative, but shy, bunch; so, let's put all that talent to good use. We are

still looking for *drawings* (no bigger than 8 ½ x 11 inches), *poems*, *short stories* from all of you (children, adults, siblings, parents, partners) to use for several artistic endeavors. Submissions can be directly about having a dysplasia or completely unrelated. We are simply looking for your input. Our first project is going to be creating a 2007 calendar; therefore, we need your masterpieces by *September 8, 2006*. Feel free to send as many examples of your creativity as you want to us either in the mail or via e-mail. All submissions will become part of our CSD Gallery. Each month we will display the original works you have submitted during Center dates so that the HSS community can view your talent and creativity.



PATIENT SATISFACTION

SURVEYS—YOUR OPINION IS VALUABLE

Nearly everyone who comes to CSD is aware that we are very interested in getting your feedback about your CSD experience(s). We are interested in your thoughts about your first visit to CSD as well as any follow up contacts with CSD. Please be assured that your answers are completely confidential. We value the feedback you provide us with as it helps us to know what is working well and what needs improvement. In our last newsletter, we told you that we would be informing you

about the results of your thoughts about our progress and areas needing improvement.

Let's break it down:

❖ Physical Space/Environment—many of you had concerns about difficulty in getting around HSS. While there is no way to physically change the size of the hospital, we can assist in making your voyage around the hospital a bit easier. With an advance phone call to Erin, prior to your appointment, we can make sure you have wheelchair escort to the Center or any other appointments at HSS on the same day as your CSD appointment. Finding the Center's location was also challenging. We now have better signage around the hospital. HSS staff is more acclimated to the Center & able to give better directions within the building. We have had some concerns about the size & décor of the examination rooms. Since these rooms are shared with so many other physicians & patients at other times of the week, we are limited in making changes. However, we are focused on what we bring into the room: respect, courtesy, food & beverages, and a high regard for the people waiting in those rooms.

❖ Timing—this was a real mixed bag of feedback. Perception is the key to this

issue. Some felt that they waited too long in the waiting room, but since no one indicated exactly how long they waited, it is hard to pinpoint the line between waiting and waiting too long. Some concerns were raised about the time it seemed to take to get appointments and/or approvals for referral recommendations. Please know that great efforts are made to get things done timely. However, sometimes there are scheduling conflicts, institutional issues, and delays that are truly beyond the efforts and commitment of the CSD staff. The area where time worked to everyone's advantage is time spent during visits. Nearly every respondent has indicated that the CSD staff spent a good deal of time with them and their families during visits.

❖ Children—we had great feedback on how children are responding to being seen in the Center. Parents like that staff speaks directly to their children. Children don't find the environment frightening.

❖ Improvements Made—given your responses, here are some of the changes that have occurred:

- Clearer Signage around HSS about the location of CSD.

❖ Involvement in your own healthcare—the gamut was wide. The majority indicates a high level of satisfaction with their own participation in their healthcare related to their CSD experience. However, those that don't feel partnered with the CSD staff in their healthcare, feel that distinction markedly.

❖ CSD Staff—nearly everyone feels a high comfort level with the manner that CSD staff addresses patients and their families as well as staff's explanation of who they are and their CSD roles. Some had reservations about staff's communication with each other, but that was a minor percentage of respondents.

❖ Amenities—people who had special needs (transportation, coming from a significant distance) felt unanimously positive that their special requirements were satisfactorily met.

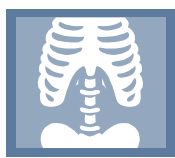
- Many requests for evaluation with a nutritionist are substantiated by our new staff member, Deborah McInerney, MS, RD, CDN.

- We have increased the number of appointments and

sessions/month that CSD patients can be seen at HSS.

- CSF Flow studies can now be performed at HSS. (Next story will explain this in greater detail).

We are appreciative of your input and hope for better CSD experiences for all of us.



CSF FLOW
STUDY
AT HSS

Many patients come to CSD with concerns about pain and decreased mobility related to spine problems. Many people have spine xrays and MRIs as part of a diagnostic workup. However, a new feature to spinal MRIs may shed some additional light as to the cause of what's bothering your spine. CSF (Cerebral Spine Fluid) is the clear, colorless fluid that travels between your brain and spine. It acts as a shock absorber between your brain and spine. During an MRI (open or closed), an additional scan can be obtained that looks at the movement of your CSF. There is no pain or risk; it just adds some more time that you are in the MRI unit. However, this increase in time in the MRI unit may provide a great deal of information to the doctors caring for you.



THAT'S ALL FOLKS !!

This concludes our latest newsletter. We are planning to send newsletters twice a year to our patients and their families. However, just as 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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