

CSD NEWS

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

Well, we have completed our first year of being the only center in the Northeast dedicated to the comprehensive medical care of adults and children with skeletal dysplasias. It seems like the right time to fill you in on what has been going on the past year and where we are headed in the next coming year(s) !!

GET YOUR RED HOT NUMBERS HERE

When we started the Center, our focus was on three major areas: patient care, education, and research. Our patients would be representative of all stages of life—from infancy through the “golden years.” To date, our patients have ranged in age from newborn to those enjoying their retirement. One third of our patients are children. Nearly all of our patients had been to other medical centers and came to CSD for another opinion. 20% of our patients have come to CSD because they have never been able to get a definitive diagnosis. The average wait for an appointment is 6 weeks due to the fact that CSD staff sees patients 2 times/month. 20% of the patients seen have been triaged to other HSS staff for treatment; several have had surgery or currently are scheduled for surgery at HSS. However, none of this could have happened without patient satisfaction.....

DID YOU FILL OUT YOUR FIRST VISIT SURVEY?

With each first visit to CSD, the patient/family is given their welcome packet. In each packet is a brochure about CSD, the CSD business card with all our contact information, a letter of welcome and a patient satisfaction survey. So how are we doing? You have told us:

- That the overall CSD experience has been “very good”. (Very good is the highest ranking of the scale on the survey).

- People were happy with the way staff addressed them and their family members.
- “Very good” was the unanimous response of how the CSD staff communicated with you as well as the manner in which you think the CSD staff communicated with each other.
- Some people found getting around HSS a bit difficult, but with clearer signs around the institution, this seems to have gotten better.

Of course, your individualized comments are amazingly important to us. Here are some of your kind and critical words:

- “The whole center was run very well and it is nice to know that this is where my daughter will be taken care of from now.”
- “I would not change one thing about the center, it was perfect.”
- “My daughter (the patient) loved the center.”
- “I found the center to be very helpful and the staff gave me the information I needed for my upcoming surgery.”
- “So far the best hospital I’ve been to in New York and I’ve lived here all my life. Thank you.”
- “I was overwhelmed by this warm and enthusiastic group who rotated in and out of the compact examination room.”

We really encourage you to give us feedback on how we are doing. Our patients are clearly a “veteran” group and we are very interested in knowing your opinion of what we are doing well and what you think we could be doing better with.

REGISTRY AND RESEARCH.....OH MY !!!

The Center for Skeletal Dysplasias' Clinical Research Registry (CSDCRR) was developed to be able to track patients prospectively, rather than retrospectively, and to collect medical information for future research studies. We hope the results of future studies will provide a better understanding of the course and nature of skeletal dysplasias, allowing us to investigate interventional approaches as well as expand scientific and clinical knowledge of skeletal dysplasias, and/or to enhance the care of people with skeletal dysplasias.

The collection and analysis of data on each patient is done using The System for Collaborative Translational Research (SCTR)®, which is a secure Web-based data collection system for clinical research. Future research will involve prospective studies of data collected on the patients seen in CSD and entered in SCTR. Patient information is collected during the patient's visit to the Center, with the patient's or guardian's permission, using genetic, orthopedic and psychosocial evaluations. We will keep you updated as to the status of this exciting, long term initiative.

HEAR YE !! HEAR YE !!
(also known as announcements)

*****Save the date*****

**MONDAY,
DECEMBER 6, 2004**

It's the 2nd Annual CSD Holiday Party at HSS. Invitations will be mailed to you soon.

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

THAT'S ALL FOLKS !!

This concludes our first 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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Volume 1, Fall 2004