University of Illinois Hospital & Health Sciences System, The College of Medicine, Division of Plastic and Reconstructive Surgery

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THE CRANIOFACIAL CENTER CHRONICLE

Celebrating 65 years of excellence in patient care
the Craniofacial Center

MESSAGE FROM THE MEDICAL DIRECTOR by Dr. Mimis Cohen

What a great year this was for our Center!

In November 2014 we celebrated the 65th anniversary of our Craniofacial Center which was established in 1949 by Dr. Sam Pruzanski, an orthodontist, who very early on recognized the importance of the interdisciplinary team model in the management of patients with clefts. He assembled a team of specialists and set the foundations of the current philosophies for short and long term management of patients with clefts. A full day of festivities was planned, starting with an educational program during which faculty members gave lectures about our experiences and clinical protocols. Speakers presented on the evolution of our Center as an interdisciplinary team of specialists, discussed advances in care and elaborated on our current treatment philosophies for short and long term treatment of patients with clefts and other craniofacial malformations. We are striving for constant improvements, aiming to provide all our patients with cutting edge care, allowing them to grow as normally as possible, and become successful in their lives.

In the evening a reception was held at the Center to thank our friends and donors for their commitment and continuous generous financial support toward patient care. This reception was extremely well attended with more than 130 people present. The Chancellor, Dr. Paula Allen Meares; the Dean of our Medical school, Dr. Dimitri Azar; the CEO of the Hospital, Dr. Avijit Ghosh and the Chief Ambulatory Officer, Mr. David Miller, among others, represented the leadership of the Institution at this great event.

Marcia Aduss and husband, Dr. Howard Aduss were honored for their instrumental role in establishing the first advisory board for the Center and for spearheading the campaign to move the Center to its current child-friendly location. Commemorative plaques were presented to the Past President of the Advisory Board of the Center (predecessor to the Face the Future Foundation), Mr. Art Catrambone, and to all past Presidents of Face the Future Foundation, Mrs., Laurie Bay, Mrs. Andrea Biel Cohen, Mr. Gus Aiello and the current president Mr. Mike Judge as a token of appreciation for their dedication to our cause, their hard work and their successful philanthropic campaigns. Due to their support we are able maintain and expand our dedicated team of specialists and our programs and provide all our patients with the highest standards of care regardless of financial coverage. (continued on page 2)

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MESSAGE FROM THE DIRECTOR OF PHYSICIAN PRACTICE

My name is Elizabeth Ellevog, Director of the Physician Practice for the Craniofacial Center. I am pleased to present the latest edition of our quarterly newsletter. Each newsletter will feature some of our clinicians who will be discussing key initiatives, new treatments, or research endeavors that will benefit our patients and their families. Our team members do not always get to share what is going on in their specialty and this newsletter is the perfect opportunity to do so.

I would also like to take a moment to introduce the newest members of the Craniofacial Team. Khristine Padiernos is a nurse coordinator who arranges all surgeries and educates patients and their families about the upcoming procedures. Lattise Tate-Smith is a medical coder for all clinic appointments and Dr. Marco Ellis is a reconstructive and microsurgeon.

I hope you enjoy this newsletter and do not hesitate to contact us for further information.

Khrisine Padiernos

Latisse Tate-Smith

Dr. Marco Ellis

MESSAGE FROM THE MEDICAL DIRECTOR (con't from page 1)

The annual gala of Face the Future Foundation was held in March and was a sold out event. Guests were moved by some of the achievements of the faculty of the Center and successes in patient care and they generously contributed. As a result the annual contribution of the Foundation for the clinical activities of the Center remained very high compared to previous years.

This year was a true financial Bonanza for the Center and our philanthropic efforts. Thanks to the donation of the late Deanna Manix Mitzemacher a very generous gift was presented to us which will be used according to the will of the trustees to afford resources to patients and their families who are underserved, advance patient care services to needy patients, physical transformation of our Center and support the innovation and discovery of our exceptionally talented physician scientists.

The Division of Specialized Care for Children (DSCC) provided us with a special large grant. This grant will be used wisely for some necessary renovations of our physical facility; by improving and updating the common spaces and the treatment rooms we will be able to make our facility more efficient and children friendly. Cutting edge equipment and instruments will also be purchased based on advanced technology which will allow us to further improve planning and execution of our procedures and achieve superior results while reducing the number of clinic visits and the subsequent loss of time in school or work for our patients and their families. This technology will also revolutionize the education of our students and trainees and assist them to further improve their skills using virtual technology for planning and execution of various reconstructive procedures.

Special thanks again to the staff of the Division of Specialized Care for Children, Dr. Mitra Dutta and the Provost's office for entrusting us with this generous grant and for their continuous support.

THE HISTORICAL UNIQUENESS OF THE CRANIOFACIAL CENTER

BY HOWARD ADUSS, DDS

There are two guiding principles that have made the Craniofacial Center a very special place. First, recognition that our patients require the attention of more than one specialist. And, second, patient care should be coordinated so that each patient receives the best possible treatment at the most appropriate time.

Today, these two very important ideas seem so obvious. But when the Craniofacial Center was organized in 1949, it was only a few years after the first conference, related to the treatment of patients with cleft lip and palate, was organized by a dentist and a speech and language pathologist. A few short years later, specialists broadened their horizons when they recognized that certain problems require the interaction of many disciplinary teams where one or more specialists take the lead in a patient's care for a period of time and are then replaced by others whose expertise are more appropriate for the changes that have taken place over time.

The interdisciplinary team is a marked departure from traditional care where the patient travels from one clinic to another. At the Craniofacial Center all the specialists come to the patient. This enhances cross-discussion of a patient's needs and facilitates coordinated care. The model established at the Craniofacial Center is now commonplace for a variety of clinical problems, but had to be learned over time.

Even the briefest history of the Craniofacial Center has to acknowledge its research and training program. In the 1950's, the Center was awarded a research and training grant by the National Institute of Health. This support allowed long-term studies of children with a variety of craniofacial malformations. These studies provided both basic and clinical information. We defined variations in morphology of patients with the same diagnosis and we modified our clinical procedures accordingly.

The innovative programs that characterize history of the Craniofacial Center form a sound foundation for its future.

SONOGRAPHY CONSULTATIONS BY TERRI KAISLING, RN, MBA

Utilizing ultrasonography for an evaluation of fetal development and abnormalities has been instrumental in assisting perinatal care. This diagnostic tool images the deep structures of the body by measuring and recording continuous high frequency sound waves without the use of radiation.

Once an ultrasound is obtained identifying a craniofacial condition (i.e. cleft lip and palate or syndromic facial anomaly), the Craniofacial Team can counsel the parents prior to delivery to discuss the condition, immediate and long term needs, and expectations of team care.

This allows parents the opportunity to ask pertinent questions, view photographs and talk with other parents regarding their child's condition prior to birth, thus decreasing anxiety.

FEEDING TIPS FOR YOUR CHILD BY ALMA MOYA, RN

Babies born with Cleft Lip and Palate, like any other babies, need to learn how to feed successfully in order to thrive and grow. The babies born with Cleft Lip and Palate have special feeding needs because these babies cannot feed from a regular nipple or breastfeed efficiently. Having a cleft palate makes it difficult to create the suction needed to suck on the nipple to get the formula out of the bottle or to latch on to the breast to breastfeed. This means that these babies are at risk for poor weight gain because they use a lot of energy to feed. Babies who are born with a cleft lip and not a cleft palate have an easier time feeding from a regular nipple and are able to breastfeed.

At the Craniofacial Center we work with parents to teach them how to feed their babies once a feeding system has been selected. Special nipples and bottles are available to feed babies born with Cleft lip and Palate. It is important to choose a feeding system that the baby will accept and that parents find easy to use. Babies should be able to feed comfortably within a reasonable amount of time, without struggling to breath, choking or working hard to get the formula out of the bottle. If the baby works very hard to feed, the baby will not gain weight because the baby uses his or her energy clamping down desperately on the nipple. In addition, if parents feel comfortable feeding and caring for their baby, this creates a positive experience for both parents and babies thereby promoting the bonding process.

Babies born with cleft lip or palate at the University Of Illinois Hospital get a visit from both the nurse and the speech pathologist as a team before discharge to ensure that babies are feeding adequately and to teach parents how to feed their babies. The nurse and the speech pathologist explain the reason for using a special feeding system and observe the feeding process to assess proper position of the baby's head and neck and to determine if the baby's chin may need to be supported. Frequent burping is important because babies with Cleft Lip and Palate tend to swallow a lot of air during feeding. Babies with a complete Cleft Lip and Palate may have formula or milk coming out from the nose. Because these babies need proper management of their special needs related to Cleft Lip and Palate, the nurse arranges the initial multidisciplinary visit at the University Of Illinois Craniofacial Center.

At the initial visit, we discuss with the parents about the team approach to treating and caring for babies born with Cleft Lip and Palate. The babies are weighed at every visit for about the first 4 to 5 months of life or longer if there is a concern about poor weight gain. The weight is plotted on a growth chart to track the babies' weight gain. If babies are not gaining adequate weight, the surgery to repair the cleft lip may be delayed until the baby's weight is back on track.

At The Craniofacial Center, a baby with Cleft Lip and Palate is seen by a multidisciplinary team which includes the plastic Surgeon, speech pathologist, audiologist, psychologist, nurse, and a dental specialist. Our team follows these babies from infancy through adolescence and young adulthood to make sure they get the services and care needed to grow and develop to reach their potential as any other child. In turn, the children become close to the team members and share their school accomplishments and involvement in other activities making our work at the center very rewarding.

SPEECH SERVICES BY ELLYN MCNAMARA, CCC-SLP

The Craniofacial Center welcomes state of the art equipment to the Speech Therapy Program in order to best meet the needs of those with craniofacial conditions. The new equipment allows CFC surgeons and speech language pathologist to visualize the speech mechanism as well as to quantify the strength of a voice in both measures of sound and pressure. The information provided by this new equipment is used to accurately diagnose speech and resonance disorders, to develop precise surgical plans and to generate invaluable data for progress monitoring that serves as essential in justification for insurance coverage for services including speech therapy, orthodontic treatment and surgical intervention. These technological advances in the assessment and intervention of speech and resonance disorders ensure that the outstanding patients at UI's Craniofacial Center receive the exceptional care they deserve.

THE CRANIOFACIAL CENTER'S 65 ANNIVERSARY AND SYMPOSIUM

FACE THE FUTURE HOLIDAY PARTY

The Face The Future Foundation (FFF) is an organization that the Craniofacial Center could not live without. We are so grateful all that they do for us. Each December the FFF hosts a holiday party for the patients and their families. Below are pictures of December 2014 holiday party. This year's holiday party is scheduled for December 12, 2015. **COME JOIN THE FUN!**

The Craniofacial Center

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http://hospital.uillinois.edu/Patient_Care_Services/Craniofacial_Center.html

Celebrating 65 years of excellence in patient care

the Craniofacial Center

Take a tour of The Face the Future' Foundation's website:

http://facethefuturefoundation.org/

PSYCHOLOGY RESEARCH BY JANINE ROSENBERG, PHD

We are pleased to announce exciting multisite research projects that have been taking place at our center. Under the guidance of our team psychologist, Dr. Janine Rosenberg, we have been running numerous NIH funded multisite studies. One of our previous projects examined the quality of life of children with cleft lip and palate, based on both parent and child reports. We followed these children and their parents for five years and learned how essential it appears to be for children to have surgeries in their teenage years in order to feel better about themselves.

A current research project assesses the development of infants with hemifacial microsomia. This project is one of the first to focus on this age and particular diagnosis. We also have a potential project scheduled to start this Fall, focusing on interviewing mothers of infants with cleft lip and palate to better understand their perception of outcomes resulting from having a cleft. Areas of study will include sleeping, feeding, breathing, and development. All of these studies give us insight into how to best help families with children with cleft lip and palate and other craniofacial conditions. The information we gain from our research enables us to provide them with the tools they need to deal with the process of transforming an afflicted newborn into a healthy, happy, and well-adapted child.

PROSTHODONTIC SERVICES BY DR. DAVID REISBERG, DDS

For more than 150 years, the maxillofacial prosthodontist has played an integral role in the rehabilitation of patients with cleft lip and palate. The normalization of speech, swallowing, and appearance for these patients relies upon this special discipline in dentistry.

In more recent years with advances in our scientific knowledge of facial growth and development, orthodontics, speech therapy and surgery these children are receiving improved care and in less time. But there is still an important role for the prosthodontist in the care of patients with cleft.

The prosthodontist may become involved with cleft patient care as early as the first week of life. Cleft lip and nose deformities may require intervention by a special dental device before lip repair to improve the outcome of surgery. The Craniofacial Center was a leader in the development of this device. Historically speaking, the earliest task of the prosthodontist was to make a special dental plate called an obturator to fill holes in the palate that could not be closed by surgery. These persistent palate openings caused speech and eating problems. With improved surgical procedures, these openings are more reliably closed and there is a much less frequent need for these obturator prostheses.

Today, the major focus of prosthodontic care is tooth replacement. It is common for teeth in the site of a cleft to be misshapen, poorly positioned, or missing. This not only affects speech and eating but appearance. Even orthodontic care with or without jaw surgery, may not resolve this situation. This is the ideal application for one of the most popular treatments today; dental implants.

An implant acts like the root of a tooth. They can be placed in bone in the site of the cleft and then be used to replace missing teeth. It is a reliable and permanent way to give patients the function and appearance that they have never enjoyed before. To enhance even more the final appearance, the shape, color, and appearance of any retained natural teeth can have custom made porcelain veneers place on them to blend all of the front teeth together for that winning smile.