One year ago Rady Children’s Hospital, with a pledge of $120 million from Ernest Rady and family, took a major step forward in pediatric research by establishing the Rady Pediatric Genomics and Systems Medicine Institute. The purpose of this Institute is to assemble a team of world-class scientists, researchers and clinicians who will focus their efforts and talents on the prevention, diagnosis, treatment and cures for childhood diseases through genomics and systems medicine and research.

In March 2015 the Rady Children’s Hospital Auxiliary voted to support this effort by establishing a $2.5 million Rady Children’s Hospital Auxiliary Endowment for Neuroscience at the Rady Pediatric Genomics and Systems Medicine Institute. The purpose of this Endowment for Neuroscience is to create financial stability for the Institute and to provide funds to help researchers and clinicians, under the direction of the endowed chair, to translate research discoveries into clinical genetics, clinical trials, DNA sequencing, bioinformatics, training, education and improved patient care and outcomes in several areas including:

- Undiagnosed Neurological Diseases
- Neurodevelopmental/Autism Spectrum Disorders
- Neuro-Oncology
- Comprehensive Epilepsy
- Movement Disorders
- Neuro-Neonatology

For more information about the Rady Pediatric Genomics and Systems Medicine Institute and additional patient stories go to www.rchsd.org

A Few Definitions

“Genomics” is the “combination of genetics and the rapidly advancing field of DNA sequencing with the goal of understanding what the data mean for the diagnosis and treatment of diseases.” “Systems medicine” is “the merging of biology and computer science in order to study genetic-based disorders in children and families.” For more information on the science of genomics, watch a video titled “The Animated Genome” at http://unlockinglifecode.org/media/animations/659#660
Greetings from the President

Our Auxiliary is one of a kind and together we truly make a difference in the lives of children and families in our community. By creating the Endowment for Neuroscience we are taking that next step, which has the potential to make a profound impact on healthcare for children both locally and worldwide.

Support for the endowment has been overwhelmingly positive. It is an honor to be a part of a group that can imagine the possibility that all children will have the best chance of leading healthy lives. Not only will we be raising funds for the endowment, we will be educating the community on this important new area of pediatric medicine. The journey towards our goal will be an exciting time for all of us. Thank you for helping the Auxiliary fulfill its mission by working in partnership with Rady Children’s Hospital-San Diego.

Cheryl Steinholt
Auxiliary President

Introducing Joseph Gleeson, MD

Dr. Joseph Gleeson will assume the directorship created by the Auxiliary's Endowment for Neurosciences. Dr. Gleeson’s lab, at the Laboratory of Pediatric Brain Disease at Rockefeller University in New York, has sequenced the DNA of more than 3,000 patients with recessive causes of diseases. With this data, the lab has uncovered more than 50 causes of disease and determined that conditions previously thought to be untreatable have potential points of treatment. Dr. Gleeson’s goal is to understand the genetic basis of diseases and conditions such as epilepsy, autism and mental disability.

A Note from Dr. Gleeson

“Thank you to the Auxiliary for your dedication and commitment to supporting the future of pediatric medicine. I am honored to return to San Diego as your endowed chair and look forward to working together to help children now and for generations to come.”

Savannah, who was diagnosed with a severe form of epilepsy known as Lennox-Gastaut syndrome, has experienced more than 27,000 seizures in her life. In 2011 her DNA was sequenced. Among 25,000 genetic variations were several mutations in her calcium-regulating genes, which could affect muscle contractions. Doctors believed they could treat her with drugs called calcium channel blockers, and they were right. Savannah’s seizures were reduced by 80%.
Imagine Yourself on the Team

In order to involve all members of the Auxiliary in the implementation of the Endowment for Neuroscience, the Auxiliary Board of Directors has appointed a Genomics Steering Committee made up of the following Auxiliary members: Cheryl Steinholt (Scripps Ranch Unit), Harriet Bossenbroek (Fuerte Hills Unit), Jeanie Scott (La Jolla Unit), Laura Stearn (North Coast Unit), Leslie Dupree (Fuerte Hills Unit), Lynne Lurie (Tierrasanta Unit), Norma Yates (Del Mar Unit), Phyllis Snyder (Bonita Unit), Shaunna Kahn (Rancho Santa Fe Unit), Vellet Wyatt Finley (Southeast Cluster Unit).

This committee has formulated solid fundraising, education and advocacy plans to meet the goals of the Endowment. Auxiliary members interested in serving on a subcommittee of the Genomics Steering Committee may contact Auxiliary President Cheryl Steinholt at 858-966-5887.

A Note from the Editor

Many of you have heard about the Auxiliary’s newest effort to support patient care at Rady Children’s Hospital, the Endowment for Neuroscience at the Rady Pediatric Genomics and System Medicine Institute. You may have read articles in the Spring and Summer 2015 issues of Chaux Talk, seen a brochure describing the Endowment, heard about patients who have received treatment following DNA sequencing, or heard the endowed director Dr. Joseph Gleeson speak at the Auxiliary’s Annual Meeting in June. Our purpose in publishing this Chaux Talk Extra, the first such issue in the history of the Auxiliary, is to bring all this information together in one place and to make it personally available to every member of the Auxiliary. We hope it inspires you to make a commitment to become part of this historic effort on behalf of our beloved Rady Children’s Hospital and the children and families it serves.

Ann Desmond, Editor

Twins Alexis and Noah were diagnosed with a rare genetic disorder that caused them to have severe and life-threatening seizures. Sequencing of their DNA led to new treatments that have helped them to have normal, active lives.

A Message from Steve Jennings

It means so much to me that the Auxiliary has chosen to make such a significant philanthropic commitment to Rady Children’s. Each of you has done so much to strengthen the hospital and prepare us for a future that is full of promise. We are truly grateful for this gift and for all that you do for Rady Children’s each and every day. The support of the Auxiliary provides is tangible, and its impact is felt throughout the hospital and our community. Thank you.

Steve Jennings
Senior Vice President & Executive Director
Rady Children’s Hospital Foundation
Imagine How You Can Make a Difference

The Endowment for Neuroscience provides an incredible opportunity for every Auxiliary member and/or Auxiliary unit to be part of an historical achievement in pediatric health care. You can make a difference by:

- Making a financial contribution
- Sponsoring or hosting a fundraising event
- Helping to spread the word about this unique and important opportunity

Call 858-966-5887, email csteinholt@rchsd.org or visit www.radychildrensaux.org.

Imagine the possibilities, and together we can bring them to life!

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**Rady Children’s Hospital Auxiliary Endowment for Neuroscience**

Providing clinical genetics, clinical trials, DNA sequencing, bioinformatics, training, education and bridge/seed funding to help treat and find cures for children with neurological diseases and disorders.

- Please contact me, I would like to make a commitment to support the Auxiliary’s Endowment for Neuroscience.
- I would like to make a commitment of ___________, payable over the next three years, to support the Auxiliary’s Endowment for Neuroscience.
- I would like to make a gift now in the amount of ___________, to support the Auxiliary’s Endowment for Neuroscience.

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Printed Name: ___________________________ Signature: ___________________________

For cash gifts (circle one): Check enclosed Credit card Bill me

Credit card number: ___________ Exp. Date: ___________

Please make checks payable to Rady Children’s Hospital-San Diego.

Thank you for your commitment to Rady Children’s.