SAINT PETER'S HEALTHCARE SYSTEM





What is a Lysosomal Storage Disease?

Lysosomal storage diseases are inherited metabolic diseases that are characterized by an abnormal build-up of various toxic materials in the body's cells as a result of enzyme deficiencies. These disorders can affect different parts of the body, including the skeleton, brain, skin, heart, and central nervous system.

Newborn Screening

By law, every baby born in New Jersey must be screened shortly after birth for genetic disorders that can cause serious health complications.

Saint Peter's University Hospital, as other hospitals in New Jersey, is mandated to screen for more than 50 genetically-influenced disorders – 44 metabolic conditions, two endocrine disorders, four hemoglobin disorders, and four others that include cystic fibrosis, congenital hearing impairment, critical congenital heart disease, and severe combined immunodeficiency. Six lysosomal storage diseases and a peroxisomal metabolic disorder known as X-linked adrenoleukodystrophy will be added to the existing newborn screening menu beginning this year.

The seven additional disorders that newborns will be screened for are:

- Fabry disease affects kidneys, heart and skin
- Gaucher disease affects liver, spleen, bones and bone marrow
- •Krabbe disease affects the nervous system
- MPS1 (Hurler Syndrome) affects heart, liver, bones, famous by the movie, *Lorenzo's Oil*, which starred Susan joints, and eyes; causes developmental issues and deafness. Sarandon as a mother seeking treatment for her son
- •Niemann-Pick disease affects spleen, liver and lungs
- Pompe disease affects the heart and skeletal muscles
- •X-linked Adrenoleukodystrophy affects the nervous system and the adrenal glands. The condition was made famous by the movie, *Lorenzo's Oil*, which starred Susan Sarandon as a mother seeking treatment for her son

"Most genetic conditions are a spectrum that can present throughout the life cycle, anywhere from *in utero* up through advanced geriatrics," says Debra-Lynn Day-Salvatore, MD, PhD, FAAP, FACMG, who chairs the hospital's Department of Medical Genetics and Genomic Medicine. "The disorders can be a medical mystery resulting in a significant delay in diagnosis. The goal of screening newborns is to test for these disorders early so that patients can be offered treatment before they start having symptoms." Early treatment is the key if life-threatening complications are to be avoided later in the child's life, adds Dr. Day-Salvatore, who chairs the New Jersey Department of Health's State Newborn Screening Metabolic Pediatric Specialty Group.

Department of Medical Genetics and Genomic Medicine: 732.745.6659 saintpetershcs.com/ GenomicMedicine The Department of Medical Genetics and Genomic Medicine oversees newborn screenings at Saint Peter's and serves as a referral center for other hospitals, pediatricians, and primary care physicians throughout the state for abnormal newborn screens. The department is home to one of the largest, most comprehensive lysosomal disease therapy centers in the United States, which recently relocated to the ground floor of the hospital.

The department's staff, which evaluates, manages and treats rare diseases identified at birth or later, is made up of physicians, genetic counselors, nurses, and a metabolic dietician. The department has provided comprehensive clinical genetic services to tens of thousands of patients during the past 27 years. During the past 14 years alone, individuals have been referred for evaluation, diagnosis, management, treatment, counseling, and emotional support for more than 2,000 different conditions.

As a state-designated regional center for newborn screening and genetic services, the department provides inpatient and outpatient services to patients of all ages with a variety of genetically-influenced conditions including abnormal newborn screens, confirmed inborn errors of metabolism, birth defects, chromosome abnormalities, hearing impairment, craniofacial and genetic bone disorders, autism spectrum, cancer, and diseases of the heart, lungs, kidneys, brain, skin, muscles, eyes, gastrointestinal and genitourinary tracts.

Saint Peter's participates in clinical trials for drugs used in the treatment of rare diseases and provides services that include a broad range of pre-conception, prenatal, and postnatal genetic counseling, as well as pregnancy-specific management and treatment of maternal metabolic, lysosomal, and genetic conditions.

Special Events

EMS Education Series MARCH 30 • 7:00 PM **TOPIC: COMMAND STRUCTURE** Call 732.745.8600, x6671 to register. Free parking and free light dinner.

National **Nutrition Month** Lecture on **Healthy Eating** March 16 10:00 AM - 11:00 AM **Crescent Park**, Spotswood (Residents Only)

March 24 **NOON - 1:00 PM North Brunswick Senior Center** (Members Only)

Annual fun-filled family event sponsored by Magic 98.3 FM radio and The Children's **Hospital at Saint Peter's** University Hospital.

Saturday, March 18 11:00 AM - 3:00 PM

College Avenue Gym

Rutgers University. New Brunswick

Visit magic983.com for more information.

Spring 👗 Auxiliary Fashion Show

Benefits the Saint Peter's Breast Center Saturday, March 25 The Pines • Edison, NJ 10:00 AM - 3:30 PM

Call 732-745-8588 or 732-672-0464

Diabetes **Alert Dav Community Mobile**

Community Calendar

For more information or to register for a program, call the contact number listed or visit saintpetershcs.com/Events.

Cancer Support

Breast Cancer Support Group

March 6 and 20 • 7:00 PM - 8:30 PM Registration required. Rutgers Cancer Institute of New Jersey Deborah Leif, MSW, LCSW 732.235.7011

Gynecologic Cancer Support Group March 14 • 7:00 PM - 8:30 PM

Rutgers Cancer Institute of New Jersey 732.235.6792

Latinos with Cancer Support Group

March 11 • 10:00 AM - 1:00 PM Sister Marie de Pazzi Conference Center Light lunch will be served. Free, but registration requested. Sessions conducted in Spanish. Call 908.658.5400 for more information.

Living with Cancer Support Group

March 8 and 22 • 7:00 PM - 8:30 PM Rutgers Cancer Institute of New Jersey Barbara Hale, LCSW • 732.235.7557

Support Groups

Alzheimer's/Dementia Caregivers Support Group March 14 • 10:00 AM - 11:30 AM

Saint Peter's Adult Day Center 200 Overlook Drive, Monroe Township Rachel Kallish, MPA, CSW, CALA 609.655.6853

Caregivers Support Group

March 9 • 1:30 PM - 3:00 PM Saint Peter's Adult Day Center Stephanie Fitzsimmon, EdN, MSN, RN, APRN-BC 732.745.8600, x8662

SHARE Support Group

(for those who have suffered miscarriage, stillbirth or neonatal death) March 16 • 7:00 PM - 9:00 PM Irina Mariano-Brown, MSW, LCSW 732.745.8522

Free Community Lectures

Understanding Chronic Pain March 14 • 1:30 PM

Presenter: Daniel Rothstein, MD, pain management, anesthesiologist Concordia Adult Community; residents only.

March 14 • 3:00 PM

Presenter: Daniel Rothstein, MD, pain management, anesthesiologist

Community Diabetes Mobile Health Support/ Services

For more information about screenings and educational programs, or the CMHS corporate flu shot program, please call 732.745.8600, x8903

Blood Pressure Screenings

Sisters Together: **Move More Eat Better Program** March 4 • 9:00 AM - 10:00 AM

Blood Pressure/ **Blood Sugar Screenings** March 1 • 2:00 PM - 3:00 PM

DeForest B. Soaries, Jr., Residences at Somerset, Franklin March 8 • 9:30 AM - 11:00 AM

South River Food Pantry March 10 • 9:00 AM - 10:30 AM

New Brunswick Senior Center March 10 • 11:00 AM - 12:30 PM Elijah's Promise Soup Kitchen,

New Brunswick March 14 • 10:30 AM - NOON

South River Senior Center March 18 • 11:00 AM - 1:00 PM Perth Amboy Christian Center March 29 • 1:00 PM - 2:00 PM

Milltown Senior Center

Blood Pressure/ **Blood Sugar/ Cholesterol Screenings**

March 14 • 2:30 PM - 3:30 PM Francis E. Parker Memorial Home, Piscataway

Blood Pressure/ Blood Sugar Screenings/ Heart Health Lecture March 6 • 10:30 AM - NOON

Quailbrook Senior Center, Franklin March 23 • 10:00 AM - 11:30 AM Charleston Place, Kendall Park. Residents Only.

Bone Density Screening

March 1 • 11:00 AM to NOON Raritan Valley YMCA, East Brunswick March 21 • NOON - 1:30 PM East Brunswick Senior Center

Hearing Screening

March 30 • 6:30 PM - 8:15 PM Highland Park Public Library

Share Your Baby's Photo on Our Billboard!

Parents of babies born at Saint Peter's University Hospital can post photos of their newborn, or in the case of multiple births, their newborns, on our digital billboard along Route 1.

For more details visit facebook.com/ saintpetersuniversityhospital

Education*

Diabetes Self-Management Education

Mondays or Tuesdays Registration and doctor's prescription required. • 732.339.7630

Gestational Diabetes Self-Management Education

Wednesdays or Thursdays Registration and a doctor's prescription required. 732.339.7630

Diabetes Support Group

The Diabetes and Hypertension Center at Saint Peter's University Hospital's Family Health Center • 123 How Lane, New Brunswick Call 732.339.7672 for more information.

English

March 14 • Noon - 1:00 PM

Spanish March 7 • Noon - 1:00 PM

Diabetes Support Group

Saint Peter's University Hospital's Center for Ambulatory Resources (CARES)

English March 16 • 10:30 AM - 11:30 AM

Parent Education

For information, fees and registration, call Parent Education at 732.745.8579, unless otherwise indicated.

Baby Care

March 19 • 9:00 AM - 1:00 PM March 6 and 13 • 7:00 PM - 9:30 PM

Breastfeeding Class March 11 • 9:00 AM - 11:30 AM

Breastfeeding Support Group

March 3 • 1:00 PM - 2:30 PM

Marvelous Multiples

March 13, 20 and 27 7:00 PM - 9:30 PM

New Mom Support Group March 3 • Noon - 1:00 PM Refreshments are served.

Prenatal Yoga and Exercise Class (four-week sessions)

Wednesdays and Fridays 7:00 PM - 8:30 PM Registration required.

Prepared Childbirth/

Lamaze Classes Wednesday and Thursday Evenings (Series) Saturday and Sunday (Single Day)

Health Services staff will provide screenings and health education.

March 28 11:00 AM - 2:00 PM Sister Marie de Pazzi **Conference Center**

Clearbrook Adult Community; residents only

Care of Your Hemorrhoids: Feel Better with Minimal Pain March 21 • 4:00 PM

Presenter: Arkady Broder, MD, gastroenterologist Saint Peter's Adult Day Center, Monroe Township



Registration required.

Sibling Class March 11 • 12:30 PM - 1:30 PM



Need a doctor? To find a Saint Peter's physician, call 1.855.SP.MY.DOC (1.855.776.9362). Also available, online scheduling with select Saint Peter's Healthcare System physicians via Zocdoc at BookMySPDoc.com This calendar is for information only. Do not rely on it to make healthcare decisions on your own; instead, talk with your healthcare provider for advice and treatment. Do not ignore medical advice or delay seeking it because of something you read here. We do not suggest or endorse that you have any tests, use products, or use other information in this document without advice from your healthcare provider.

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RECOGNIZED

and the

Saint Peter's Healthcare system

254 Easton Avenue, New Brunswick, NJ 08901 732.745.8600 800.269.7508 saintpetershcs.com

Catholic hospital sponsored by the Diocese of Metuchen

State-designated children's hospital and regional perinatal center





American Diabetes Association。

*The American Diabetes Association Recognizes this education service as meeting the National Standards for Diabetes Self-Management Education and Support



LEAPFROG

HOSPITAL

SAFETY FALL 2016 GRADE