Medical Xpress

U-M to develop guide for parents of children with disorders of sex development

January 16 2013

When a child is born with a disorder of sex development, decisions regarding gender assignment and genital surgery are often made quickly and under pressure.

Quite often those decisions are surgical and often irreversible. Former patients and health care advocates have long complained that parents are provided inadequate information to make decisions for their child with a disorder of sex development.

But with a new award from the Patient-Centered Outcomes Research Institute (PCORI), researchers at the University of Michigan hope to provide parents with the tools needed to make decisions about disorders of sex development (DSD).

"When a child with a disorder of sex development is born, parents are often experiencing enormous distress," says David E. Sandberg, Ph.D., director of the Division of Child Behavioral Health at C.S. Mott Children's Hospital and professor of pediatrics and communicable diseases at the University of Michigan Medical School.

"The right decisions about gender assignment—is it a boy or a girl—and the best course of action (for example should there be surgery? what kind? when?) are not obvious."

"Parents can make decisions that they think are in the best interest of the child that they will regret later."

DSD is a term that describes a wide range of diagnoses that affect the development of sex organs, whether due to chromosomes, hormones, or other factors.

Sandberg said despite significant progress, genetic diagnosis does not necessarily offer clear guidance for parents about gender assignment or best treatment. "It can open the door to additional uncertainties," he says.

Sandberg's project, which has a proposed budget of about $1.3 million, would create a decision-making aid that could be used in genetic counseling and test-result disclosure that would prepare parents to be fully involved in management or treatment plans for their children.

"We want to support parents becoming actively involved in making those decisions, and reduce the likelihood of future worry and regret about decisions that have been made," he says, adding that the guide will educate families about sex development of the body, how disorders are diagnosed (especially how to interpret genetic test results), and possible relationships between diagnostic/genetic testing, decisions about care, and known consequences of those decisions on their child and entire family.

Sandberg plans to introduce the decision-making guide into care for persons affected by DSD and evaluate its effectiveness through an existing network of medical centers supported by the National Institute of Child Health and Human Development. The DSD – Translational Research Network is comprised of health care providers and researchers at the University of Michigan/C.S. Mott Children's Hospital, UCLA, UCSF, Seattle Children's Hospital and other medical centers.

PCORI funded the project as part of an effort to help patients make better-informed health decisions.

"Today marks a major milestone in our work as we build a portfolio of comparative clinical effectiveness research that will provide patients and those who care for them better information about the health care decisions they face," said PCORI Executive Director Joe Selby, MD, MPH. "These research projects reflect PCORI's patient-centered research agenda, emphasizing the inclusion of patients and caregivers at all stages of the research."

PCORI is committing $40.7 million in funding for a slate of 25 projects, which were approved by PCORI's Board of Governors following a competitive, multi-stage review process involving scientists, patients, caregivers and other stakeholders. Proposals were evaluated on the basis of scientific merit, engagement of patients and stakeholders, methodological rigor and fit within PCORI's National Priorities for Research and Research Agenda.

The awards were part of PCORI's first cycle of primary research funding and selected from among nearly 500 completed applications submitted earlier this year. All proposals were approved pending a business and programmatic review by PCORI staff and completion of a formal award contract.

More information: More information is available at: www.mottchildren.org/medical-s … peds-sex-development

Provided by University of Michigan Health System