

Fall Newsletter

ACCORD ALLIANCE CELEBRATES ITS FIRST YEAR

We've had a busy, productive year since we opened our doors in June 2008:

- ✓ We welcomed new and long-time supporters in Boston, Ann Arbor, San Francisco, and New York City to share our mission, forge new partnerships, and establish a presence across the country.
- ✓ We collaborated with the University of Michigan Medical School to hold the *Disorders of Sex Development (DSD) Research and Quality Improvement Symposium*, where over sixty health care providers, researchers, patients, and family advocates worked together to establish a collaborative network and build consensus on a national agenda for DSD research and quality of care improvement.
- ✓ We launched a new website in January 2009. Look for our next version in September 2009 – with a new and improved look and even more information (www.accordalliance.org).
- ✓ We made educational and resource materials available to national and international colleges and universities – improving the information included in course curricula and library archives.
- ✓ We recently served as a resource to ABC News and National Geographic Television – consulting on DSD-related issues for the development of programs related to DSD and the science of gender.



A MESSAGE FROM JANET GREEN, OUR NEWEST BOARD MEMBER



Janet recently joined our Advisory Board as a patient advocate representative. As a person with Congenital Adrenal Hyperplasia (CAH), Janet is sensitive to and passionate about the needs of patients, families, and physicians. She was a contributor to the international consortium on the creation of the "Clinical Guidelines for the Management of DSD in Childhood." Currently, Janet is a trustee of Continuum Health Partners in NYC, a member of the Board of Overseers of Beth Israel Medical Center in New York, and co-chair of the Phillips Beth Israel School of Nursing. Previously, she was a board member of the CARES Foundation.

"Occasionally in life we get the benefit of a perfect fit, and that's exactly how I've felt since joining Accord Alliance's Board. My years of advocacy work taught me the value of collaboration – which is the cornerstone of Accord Alliance's mission. Bringing together patients and care providers while offering the most up to date information, research and literature about DSD – this is Accord Alliance.

As we participate in conferences, promote a patient-centered model of care, connect people in our community, observe trends and shifts in thought, we are diligently promoting comprehensive, integrated approaches to care that enhance the health and well-being of people and families affected by DSD. I am thrilled to be a part of Accord Alliance.

My virtual door is always open, so please contact me anytime at janet.green@accordalliance.org."

Janet Green

OUR PLANS FOR THE FUTURE ARE EXCITING

- In October we start a project with the University of Michigan Medical School and the Michigan Center for Congenital Adrenal Hyperplasia (MICCAH). MICCAH develops educational content for providers, affected persons and their families, and the general public. We will enhance a CAH care manual and develop clinical training materials for three sites with interdisciplinary teams that will include pediatric endocrinologists, nurse clinicians, social workers, and behavioral health experts. We will also provide assistance in developing materials for the MICCAH website.
- We will continue to expand our website, casting a wider and deeper net with more information for all of our stakeholders. We will continue to update our materials, broaden our audience, provide new and cutting-edge information, and foster a sense of community in the DSD world.
- We will convene expert panels to expand the *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* and the *Handbook for Parents*. Keeping these tools up-to-date and actionable will help us remain responsive to the growing number of requests for information on DSD and tools to improve treatment and care.
- We are collaborating with the Phillips Beth Israel School of Nursing to develop a model course for honors nursing students on effective methods of caring for patients and families affected by DSD.
- We will continue to partner with universities and other organizations to participate in grant opportunities to support research and programmatic initiatives aimed at improving DSD healthcare and outcomes.

"Before I found Accord Alliance, I spent days and nights worrying about our daughter's future, all due to lack of knowledge in the medical community about her DSD. Finding Accord Alliance gave me hope that no other parent will have to go through what we went through the first few weeks of our daughter's life. I am so grateful to have them as a resource and am so very proud of the work that they do."

Sarah C
A Grateful Parent



Accord Alliance
www.accordalliance.org

**Click on the button
below to contribute**



Together we can:

Continue to reach new parents and families;
Support interdisciplinary teams and foster patient and family-centered care;
Ensure better care, better outcomes, and better lives for all families.

398 Columbus Ave #294
Boston MA 02116
(617) 488-9770
email: info@accordalliance.org

WE NEED YOUR HELP TO SUCCEED !

We remain deeply committed to improving healthcare for patients and families affected DSD. Without your continued support we will not be able to continue our efforts.

Current funding from The California Endowment start-up grant, the primary source of funding for our first two years, comes to an end at the beginning of 2010. We are actively seeking support from individuals, foundations, and state and federal grant agencies to extend our work beyond 2010.

In order to continue our efforts to provide DSD educational materials and foster the development of interdisciplinary healthcare teams through and beyond 2010, we have set an ambitious but necessary fund-raising target of \$300K for the next year.

"Optimal care for persons requiring lifelong healthcare, including those born with DSD, requires comprehensive and interdisciplinary healthcare delivered by teams that communicate well amongst themselves and with their patients and families. This does not come easily in the current healthcare environment. By convening and engaging all stakeholders with an interest in enhancing care for DSD, Accord Alliance offers an important opportunity to work together to improve healthcare and quality of life outcomes for those people affected by DSD and their families."

David E. Sandberg, PhD.

*Associate Professor & Director, Division of Child Behavioral Health, Pediatrics & Communicable Diseases, University of Michigan
Member, Accord Alliance Advisory Board*