

HISTORY OF DOWN SYNDROME ALABAMA

History of Down Syndrome Alabama - DSA (formerly Parent Advocates Down Syndrome (PADS))

Down Syndrome Alabama, (DSA) has a long history of significant support for individuals with Down syndrome in Alabama. For more than 35 years DSA programs have been constructed with foresight to serve individuals with Down syndrome over an entire lifetime. These programs are also designed to directly impact family members, caretakers, educators, medical professionals, service providers and communities.

Formerly known as Parent Advocates Down Syndrome – PADS finds its origin in the 1970's, where founding parents worked hard as advocates for their children even before the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) were officially legislated. The formation of a board of directors and the implementation of governing by-laws led the way to incorporation and a 501(c)3 not-for-profit status. For two decades this group was an engaging and driving force for early intervention, classroom inclusion and medical care for the unique needs of infants and children with Down syndrome. Specifically, PADS played an integral part in the founding and initial formation of the Children's Down Syndrome Clinic at Children's Hospital here in Birmingham.

The group lapsed into a dormant state during the 1990's and was re-energized and re-organized beginning in 1999. With a complete rewrite of the by-laws and participation in the National Down Syndrome Society's Buddy Walk, the organization quickly re-emerged as a solid force of advocacy for the Down syndrome community. Increased financial accountability and organizational stability provided a secure foundation for support groups for all ages, prepared a platform to offer seminars and workshops, created a pathway for implementing communication venues and necessitated the creation of promotional materials.

Having experienced the benefits and positive outcomes of earlier advocacy efforts, two PADS members approached the University of Alabama in Birmingham (UAB) Department of Genetics about establishing medical and mental healthcare specifically for individuals with Down syndrome once they 'outgrew' the already established Children's Down Syndrome Clinic or their attending pediatricians. Bruce Korf, M.D., Ph.D., chair of the department, was receptive to the idea and seeing the legitimacy, necessity and urgency of their request, encouraged them to pursue a path for realization of this proposal.

A committee was formed, representing parents and professionals, to further study the needs and possibilities of such a venture. Research quickly revealed a pioneering adult Down syndrome clinic located in Chicago. The entire committee traveled to Atlanta in the summer of 2006 to meet with the founders of this clinic, Brian Chicoine, M.D., and Dennis McGuire, Ph.D. At the conclusion of this session the doctors most graciously agreed to speak about their experience and share their vision with the larger group in Birmingham.

In December of 2006, PADS coordinated a large gathering of medical professionals and then later hosted an educational seminar featuring Drs. Chicoine and McGuire in February of 2007. At the conclusion of these two significant events it became clear that the clinic in Birmingham was soon to become a reality. UAB's Department of Genetics; agreed to house the project, appointed Dr. Edward Lose, M.D. as the clinic director and commenced a search for adult medicine doctors who would actually attend patients. The formulating committee then evolved into an Advisory Board offering continuity and cohesive leadership. From the clinic's inception PADS was a key funder of its operations, providing philanthropic gifts to ensure a continuous pursuit of quality medical and mental healthcare for adults with Down syndrome.

As this project became a reality, PADS was experiencing equal growth in an active mailing list that topped 600 members. Outreach was expanded through an active website and the creation of awareness programs for schools, companies and civic groups. PADS hosted its first of what would become an annual offer, accredited conference in order to increase education and support for parents, educators and medical professionals. In 2008 PADS saw the need to hire a full-time executive director. PADS members along with the Birmingham community caught vision for the necessity of the adult clinic, through increased awareness at an annual Charity Golf Classic and by raising over more than \$85,000 annually at the Buddy Walk.

HISTORY OF DOWN SYNDROME ALABAMA

For seven years PADS, in partnership with the Genetics Department supported the Adult Down Syndrome Clinic at the Sparks Clinic in the Civitan Building on the campus of UAB. After extensive deliberation, the Board of Directors of Parent Advocates Down Syndrome came to the difficult conclusion in May of 2013 that they could no longer fund the adult clinic. The Board came to this collective decision after a thorough review of the ADSC's scope and operations, a discussion of possible alternative models and modified staffing arrangements, and a frank appraisal of PADS ability to financially support the clinic.

The experience gained over those seven years has and will be invaluable in helping PADS to understand the medical and mental healthcare needs of their constituents. PADS will always deeply appreciate the clinic staff for their exceptional commitment to improving the health of those with Down syndrome. In June of 2013 Parent Advocates Down Syndrome changed their name to Down Syndrome Alabama (DSA). It is now DSA's responsibility and goal to apply the extensive knowledge gained at the adult clinic to new efforts that they hope will address the needs of teens and adults with Down syndrome across Alabama.

This vision includes but it is not limited to medical and mental health care. Actually it is a broad perspective for the well-being of the "whole" adult over their lifetime: Transition resources and life planning after high school -The offering of education and social activities - The creation of a communication network and promotion of community inclusion - Remembering and giving attention to the oldest members of our organization. We are calling this collection of initiatives - The John Mark Stalling Adult Advocacy Program.

Football gave Alabama one of its most beloved coaches, Gene Stallings. Coach Stallings gave Alabama his tireless efforts as an advocate for Down syndrome since the birth of his son, John Mark, in the early 1960's. Sadly John Mark passed away at the age of 46 in August of 2008; his life was a vibrant example of the long and full life individuals with Down syndrome can lead when provided with access to quality medical care and support services. We are so grateful to Coach Stallings and his wife, Ruth Anne for their permission to name all DSA programs for older teens and adults with Down syndrome in honor of John Mark.