Goal 1 Action Plan

"Educate providers, policymakers, insurance providers, medical/health career students, the public, affected families, and university and high school students regarding genomics, local genetic resources, genetic services (availability, access, indications, and benefit) and the process of referring for genetic services."

Objective 1 - The OSDH Genetics Program, in collaboration with OGAC, will establish and maintain a genetics education **resource center** to facilitate the education of health care providers and the public on genetic services and resources.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ Develop and publicize a genetics speakers' bureau (for use at all levels from physician to high school students (priority number 5).
- ○ Develop or identify genetics educational tools for high school students.
- ○ Develop or identify a genetics self-study guide for health care providers.
- ○ Maintain and continue to develop the OSDH genetic Web site as a resource for local genetic services, genetics education for the public and health care providers, updates on technology advances, and family support and resource information (the Family Advisory Committee will provide oversight of the Web site development of the family resource section).
- ○ Develop a practitioner manual for newborn (hearing and metabolic) screening program.
- ○ Develop educational brochures about genetics:
  - i. Benefit and indications for clinical genetic services throughout the lifecycle to assist in educating insurers and policymakers.
  - ii. Genetics as a career for high school and college students.
  - iii. Teratogen hotline information to include promotional items, such as magnets.
- ○ Develop and identify existing family resource guides that include services for children with special health care needs and genetic resources.

Objective 2 - The OSDH Genetics Program will develop an organized **education campaign** for the public and health care providers to include lectures, community forums, publications, and hospital in-services.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ Secure a full-time educator (preferably a board-certified genetic counselor) for the OSDH Screening and Special Services programs of newborn screening (hearing and metabolic), birth defects registry, and genetics (priority number 1).
- ◇ Develop and provide ongoing genetic educational programs, including genomics, for public health and health care providers utilizing the national guidelines developed by CDC and NCHPEG to include (priority number 2):
  - i. Co-sponsor genetics educational efforts with GECO, MOD, HA Chapman Institute of Medical Genetics, OUHSC, and other local organizations.
  - ii. Develop a public health sponsored annual genetics seminar collaborating with professional organizations targeting physicians, specifically family practice, internist, and pediatricians.
  - iii. Collaborate with existing distance-learning programs to develop a strategy to offer genetic education programming for providers.
  - iv. Collaborate with professional organizations to include genetic presentations or articles in their publications or seminars.
  - v. Annually by the end of the first quarter, notify high schools, universities, medical/career programs, hospitals, medical/career associations, and community organizations of genetic educational offerings.
  - vi. Provide lectures upon request.
- ○ Provide a minimum total of 12 genetic lectures and/or forums to high schools, universities, medical/career programs, the public, hospitals, and medical/career associations per year.
- ○ Develop a hospital in-service program for newborn screening and birth defects registry surveillance programs of OSDH and provide every 12 to 24 months and as needed.
- ○ Develop and distribute Screening and Special Services publications that will facilitate access to services and education efforts:
  - i. Publish an annual Screening and Special Services program newsletter featuring articles on newborn screening (metabolic and hearing), birth defects registry, lead poisoning prevention, and genetics.
  - ii. Distribute the *State Genetics Plan* to policymakers, health care providers and post on the OSDH Web site.

Objective 3 - The OSDH Genetics Program will collaborate with the public, professionals, and OGAC to **maximize genetics education opportunities** in Oklahoma.

Action Steps (◇ symbol identifies prioritized action steps):

- ◇ Contact and establish relationships with insurers to provide education on reimbursement issues related to newborn screening and genetic services, such as genetic counseling, lab utilization, and newborn screening fee (priority number 3).
- ◇ Collaborate with OUHSC faculty to encourage the incorporation of genetic courses into the curriculum of medical schools, nursing, and allied health (priority number 4).
- ○ Identify opportunities to offer genetic education offerings by networking with the following organizations and programs:
  - i. Oklahoma Turning Point Initiative
  - ii. March of Dimes
  - iii. OUHSC outreach education programs
  - iv. Family Voices
  - v. Early Intervention
  - vi. Children with Special Health Care Needs Program
- ○ Develop relationships with undergraduate programs and local public high schools to advocate for the incorporation of genetics into the curriculum and publicize genetic career options.
- ○ Collaborate with Public Health Policy Committee of OGAC to identify educational opportunities for policymakers, i.e., education offerings at the Capitol.

Objective 4 – The OSDH Genetics Program will facilitate collaboration with the Oklahoma Births Defect Registry, Women's Health Service, Chronic Disease Service, OGAC Birth Defect Registry, Prenatal Screening and Diagnosis Committee, and the March of Dimes (MOD) in the development of a **statewide program of preconception and prenatal health education** to identify populations at risk and to provide education about the prevention of birth defects and adverse birth outcomes.

Action Steps:

- Develop recommendations to implement prenatal screening for cystic fibrosis.
- Develop a pamphlet on prenatal screening for cystic fibrosis.
- Develop a public education campaign targeting high school students and family planning program clients regarding the prevention of birth defects and prematurity related to teratogen exposures such as alcohol and smoking.
- Maintain and expand the public health prevention of neural tube defects campaign.
- Collaborate with the update of the "Diabetes and Pregnancy Health Expectations Guidelines," and facilitate the implementation of the guidelines statewide.
- Develop and implement a preconception screening tool statewide.

This is the Spannagel family.
Their story begins on page 34.