

Development of the Regional National Birth Defects Action Coalition

Birth defects are common, costly, and critical. Every 4 ½ minutes a baby is born with a birth defect in the US. We need help educating others and raising awareness about this important issue.

The National Birth Defects Prevention Network's Parent Advisory Group (PAG) is a group of parents and stakeholders working together to help raise awareness about **all** structural birth defects (e.g., congenital heart defects, cleft lip and palate, spina bifida, etc.). This group strives to educate others, including legislators and key decision-makers, about issues affecting individuals with birth defects and their families.

In order to have a larger and stronger impact, the PAG is developing the National Birth Defects Action Coalition (NBDAC). This Coalition includes parents and other stakeholders who want to help educate legislators and other key decision-makers. These individuals are willing to share their stories and experiences to mobilize and advance policies that positively impact birth defect-related issues. This Coalition will be organized into regions across the United States.

The PAG is searching for parents who are willing to be a Regional Leader and whose duties will include the following:

1. Be the point person for the region (we estimate 10-15 hours per month);
 - a. Participate in an initial training webinar for all Regional Leaders (approximately 60 to 90 minutes)
 - b. Quarterly conference calls (approximately 1 hour each)
2. Communicate with the PAG and state specific surveillance program staff to identify state representatives (the PAG will help connect you with that staff);
3. Work on a dissemination plan for information (region to state);
 - a. Discuss and disseminate information from the PAG about all structural birth defects
 - b. Disseminate information from the PAG to the parents and healthcare workers in his or her region
4. Share his or her family's story (able to bring their personal experience and knowledge from their own life and to use their story to discuss broader terms of all structural birth defects);
5. Be the press release contact or assist state leaders with press release(s) and work to get press releases disseminated in appropriate media outlets (approximately 90 minutes); and
6. Assist with building the March of Dimes (MOD) Local Chapter family story (with topic-specific photographs and documentation via: media stories, advocacy, education, and connecting families with MOD chapters).

Please consider sending this information along with the NBDAC Committee Application to anyone who may be interested, including you.

Should you have any questions, please feel free to contact Marcia Feldkamp at Marcia.feldkamp@hsc.utah.edu

Region		Name	States
1	Great Plains	Great Plains Genetic Service Network (GPGSN)	Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, South Dakota, Oklahoma
2	Southeast	Southeast Regional Genetics Group (SERGG)	Kentucky, Tennessee, North Carolina, South Carolina, Georgia, Florida, Alabama, Mississippi, Louisiana
3	Mountain States	Mountain States Regional Genetic Service Network (MSRGSN)	Arizona, Colorado, Montana, New Mexico, Utah, Wyoming
4	Great Lakes	Great Lakes Regional Genetics Group (GLaRGG)	Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin
5	Mid-Atlantic	Mid-Atlantic Regional Human Genetics Network (MARHGN)	Delaware, Maryland, New Jersey, Pennsylvania, Virginia, Washington D.C., West Virginia
6	Empire State	Genetics Network of the Empire State	New York, Puerto Rico and the Virgin Islands
7	New England	New England Regional Genetics Group (NERGG)	Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont
8	Pacific Northwest	Pacific Northwest Regional Genetics Group (PacNoRGG)	Washington, Oregon, Idaho, Alaska
9	Pacific Southwest	Pacific Southwest Regional Genetics Network (PSRGN)	California, Hawaii, Nevada
10	Texas	Texas Genetics Network (TEXGENE)	Texas

National Birth Defects Action Coalition
Regional Leader – Application



Name: _____ State: _____

Contact Information: Home phone: _____ Cell phone: _____

Email: _____

What type of birth defect was your child born with? _____

Please list your volunteer or professional work experience (ex. Boy Scouts, Girl Scouts, Community Volunteering):

Offices held during volunteering for these groups: _____

Give a brief history of your group and what advancements have been made during the life of your group (number of members, attendance, number of meetings per year): _____

What is your interest in this Action Coalition: _____

Do you have advocacy experience? Please describe: _____

What do you consider to be your skills/knowledge/experience to develop relationships with legislators and organizations at a state or national level? _____

Have you worked directly with state or national health policy leaders, i.e., birth defects surveillance programs, children's medical services programs and/or maternal/child health programs? If yes, briefly describe your activities: _____

Can you put forth the time it will take to fill the position?

Explain: _____

Any other information you may have that you feel is important to better qualify you for this position:

Signature: _____

Date: _____