

Trans-NIH Structural Birth Defects Working Group CHARTER

Vision: Current estimates are that one in 33 infants born in the United States has a birth defect. Birth defects are the leading cause of death for infants during the first year of life. The Trans-NIH Structural Birth Defects Working Group (SBDWG) brings together extramural program officials from NIH Institutes and Offices whose missions include research into structural birth defects, with the ultimate goal of facilitating advances in our understanding of the etiology, mechanisms, epidemiology, prevention, and treatment of structural birth defects.

Purpose: With structural birth defects research funded by numerous NIH Institutes, the SBDWG serves to better communicate and coordinate efforts across the NIH by:

- Leveraging existing scientific resources by enhancing communication between representatives of networks, consortia, and groups
- Exploring collaborations and activities that will advance research efforts through a coordinated effort
- Optimizing investments in research to maximize the impact of future funding
- Liaising with other Federal agencies (e.g., CDC), organizations (e.g., March of Dimes), and societies (e.g., Teratology Society, Society for Developmental Biology) with an interest in birth defects research

Goals: Short-term goals focus on building awareness and a scientific consensus across many disparate research areas regarding the state of the science, emerging priorities, and research gaps; long-term goals focus on sustaining forward momentum across the broad spectrum of structural birth defects research through knowledge sharing and cross-disciplinary collaborations by:

- Ensuring widespread dissemination to program staff and the extramural research community of the white paper summarizing findings and recommendations resulting from the January 2014 workshop, Developing an Interdisciplinary Research Agenda for the Genetics of Birth Defects [funded by NICHD, NIDCR, NIEHS, and NCATS/ORDR through 1U13HD076529-01]
- Using the findings of the 2014 workshop to identify short-term (five-year) and long-term (10-year) goals for NIH stewardship of birth defects research; developing strategies to implement achievement of these goals based on individual Institute/Office and NIH priorities
- Developing a trans-NIH RCDC compatible definition (“fingerprint”) for congenital anomalies/birth defects
- Encouraging collaborations between basic scientists and clinicians studying structural birth defects [e.g., see PA-14-056 which includes participation by NICHD, NIAAA, NIDCR, NIDDK, NIEHS, and ODS]
- Expanding the biennial NICHD Structural Birth Defects Meeting to include more broadly NIH-funded basic and clinical birth defects researchers in the short term and transitioning this meeting to a national forum open to all interested researchers in the long term
- Working with the extramural research community to establish a sustainable meeting format open to all basic scientists and clinicians with shared interests in structural birth

defects research across all organ systems to promote this area of research on a national and international level

Membership: The SBDWG is comprised of key stakeholders from the NIH Institutes and Offices with the expertise and information needed to advance the goals of the group including, but not limited to, representatives overseeing existing grant portfolios, consortia, networks, and groups in the area of structural birth defects research. Membership could include:

- NICHD, which, because of its broad perspective of the whole child starting from preconception through pregnancy, birth, and childhood will coordinate the SBDWG;
- “Organ-specific” Institutes such as NEI, NHLBI, NIAMS, NIDCD, NIDCR, NIDDK, and NINDS by virtue of their missions to study congenital conditions related to these organs;
- Other Institutes or Offices such as NHGRI, NIBIB, NIEHS, or ORDR whose missions support the study of structural birth defects;
- Institutes such as NCI, NIAAA, NIDA, NIMH whose constituencies include special populations affected by structural birth defects; and
- Any other NIH Institute, Center, or Office with an interest in advancing the goals of the SBDWG such as ODS.

SBDWG members will be appointed by their Institute Director, and members will be expected to act as a liaison between their Institute leadership and staff and the SBDWG to further the goals of the SBDWG.

- Ex Officio members from other Federal agencies with a shared interest in structural birth defects research such as the Centers for Disease Control and Prevention.

Decision Making Process:

- Any member of the SBDWG may bring forward action items to be discussed by the group.
- Members are expected to liaise with their Institute Director and staff to provide feedback for SBDWG discussions.
- Recommendations developed by the SBDWG will be given to the Director, NICHD to share with all Institute Directors via the appropriate IC Directors’ forum.
- Final implementation of any recommendations will be at the discretion of the individual Institute Directors.