

**Virginia Newborn Bloodspot Screening New Disorders Workgroup:**  
Mucopolysaccharidosis Type II (MPS-II) & Guanidinoacetate Methyltransferase Deficiency (GAMT)

**Tuesday, December 10, 2024**

**12:00 PM – 4:00 PM**

**Location: Virtual**

**Virtual Platform: Zoom Meeting Registration: [https://www.zoomgov.com/webinar/register/WN\\_ZqE1legHQa2kjTjJmdVXCg](https://www.zoomgov.com/webinar/register/WN_ZqE1legHQa2kjTjJmdVXCg)**

**AGENDA**

**Members (check = present):**

- |  |   |
|--|---|
| <input type="checkbox"/> Dr. Bill Wilson, UVA Genetics                   | <input type="checkbox"/> Kim Pekin, Certified Practicing Midwife                    |
| <input type="checkbox"/> Dr. Alice Basinger, EVMS/CHKD Genetics          | <input type="checkbox"/> Rebecca White, Midwife, American College of Nurse Midwives |
| <input type="checkbox"/> Dr. Christina Grant, CNMC Genetics              | <input type="checkbox"/> Eileen Coffman, Registered Dietician                       |
| <input type="checkbox"/> Dr. Paldeep Atwal, VCU Genetics                 | <input type="checkbox"/> Lisa Shaver, Nurse, VCU                                    |
| <input type="checkbox"/> Dr. Marta Biderman Waberski, INOVA Genetics     | <input type="checkbox"/> Abraham Segres, VHHA                                       |
| <input type="checkbox"/> Amy Brooks, VCU Genetics                        | <input type="checkbox"/> Jana Monaco, NORD, Parent Advocate                         |
| <input type="checkbox"/> Dr. Nayef Chahin, VCU Neonatology, Virginia AAP | <input type="checkbox"/> Roslynn Garvin, Parent                                     |
| <input type="checkbox"/> Dr. Richard Bennett, Community Pediatrician     |   |
| <input type="checkbox"/> Robert and Amanda Atkins, Parent                |   |

**VDH & DCLS Staff**

- |  |  |
|--|--|
| <input type="checkbox"/> Jennifer Macdonald, VDH | <input type="checkbox"/> Emily Hopkins, DCLS     |
| <input type="checkbox"/> Mary Lowe, VDH          | <input type="checkbox"/> Leigh-Emma Lion, DCLS   |
| <input type="checkbox"/> Rebecca Edelstein, VDH  | <input type="checkbox"/> Paul Hetterich, DCLS    |
| <input type="checkbox"/> Clair Seckner, VDH      | <input type="checkbox"/> Christopher Nixon, DCLS |
| <input type="checkbox"/> Victoria Goynes, VDH    | <input type="checkbox"/> Richard Haughton, DCLS  |
| <input type="checkbox"/> Tyrique Carden, VDH     | <input type="checkbox"/> Aki Harada, DCLS        |

**Guest Speakers / Observers**

Dr. Matthew Ellinwood, National MPS Society  
Heidi Wallis, Association for Creatine Deficiencies (ACD)

12:00-12:10	Welcome: A. Call Meeting to Order B. Roll Call of Workgroup Members C. Review of Agenda
12:10-12:20	Public Comment
12:20-12:40	HHS Secretary’s Advisory Committee Stance A. Addition of MPS-II to RUSP B. Addition of GAMT to RUSP
12:40-1:20	Workgroup Overview A. Virginia Administrative Code Review B. Virginia Newborn Bloodspot Screening Program 101 C. Implementation of Screening for New Disorders D. Disorder Overview
1:20-1:50	Guest Speakers: MPS-II A. Clinical Perspective, Dr. Matthew Ellinwood B. Parent Perspective, Roslynn Garvin
1:50-2:00	BREAK
2:00-2:30	Guest Speakers: GAMT A. Clinical Perspective, Heidi Wallis B. Parent Perspective, Amanda and Robert Atkins
2:30-3:15	Programmatic Impacts, VDH & DCLS Staff A. Laboratory Consideration B. Follow-Up Consideration

	C. Financial Impact
3:15-3:30	BREAK
3:30-4:00	Workgroup Recommendations A. Open Discussion B. MPS-II Recommendation C. GAMT Recommendation
4:00	Adjournment A. Review Action Items/Next Steps