

August-November Topic #2: Developmental Delays & Genetics



Wow! Can you believe it, we just completed 4 months and Topic #1 (Red Flags 4 Genetics). We hope you enjoyed this inaugural session of the Time 4 Genetics Program.

If you have not yet had a chance to provide feedback through the **evaluation/survey**, please take about 10-15 minutes to share your honest feedback with us so we can continue to improve Time 4 Genetics as we head into this next topic and as we recruit our second cohort of clinics.

This month, we kick off Topic #2: **Developmental Delays & Genetics**

"With a combined prevalence of ~17% among 3- to 17-year-old children in the United States, neurodevelopmental disabilities are the most prevalent chronic medical conditions encountered in pediatric primary care." (source & source)

For the next 4 months we will explore the topic of Developmental Delays and Genetics in various ways:

August: Newsletter (you are reading it now!)
September: Webinar (see details below)
October: Check your Snail Mailbox!

November: Family Centered Perspectives

Please take an hour (or more!) to review the resources in this newsletter. Also, please feel free to forward this newsletter on to a colleague and invite them to **APPLY** (click button below) to be part of cohort #2 of Time 4 Genetics clinics (Deadline is November 15th/ Cohort #2 starts March 2022).

We thank you for taking TIME 4 GENETICS!

Time 4 Genetics Application for Cohort #2 due 11/15/21

Survey Link to Provide Feedback for Time 4 Genetics and Topic #1: Red Flags

Time 4 Genetics Library (Archive of Topic #1)

Save the Date: September 30, 2021 (at 11am PT, noon MT, 1pm CT, and 2pm ET)

Webinar: Developmental Delays & Genetics

Please Join Us:

September 30th

(at 11am PT, noon MT, 1pm CT, and 2pm ET)

for the webinar for the Time 4 Genetics Initiative

The webinar topic will be:

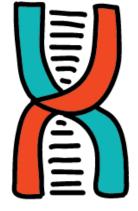
Developmental Delays and Genetics

The guest presenter is:

Austin Larson, MD a geneticist at Children's Hospital Colorado

Register for the Webinar Here

Resources for TOPIC #2: Developmental Delays & Genetics



Just Published!!

ACMG Practice Guideline:

Exome and genome sequencing for pediatric patients with congenital anomalies or intellectual disability: an evidence based clinical guideline of the American College of Medical Genetics and Genomics (ACMG)

Genetics in Medicine (2021)



MSRGN's Developmental Delay Algorithm Toolkit

In 2018, MSRGN convened a workgroup to develop this **Developmental Delay Algorithm** for Primary Care Physicians in our region. In addition, resources were developed for families and providers to discuss genetics in the primary care setting (including consent for testing, genetic legislation, handouts for families on VUS and genetics and webinars on types of genetic testing. The algorithm and all those related resources can be found **here.**



AAP's Publication: Comprehensive
Evaluation of the Child With
Intellectual Disability or Global
Developmental Delays

Though this publication is from a few years back it is the most recent AAP guidance on Developmental Delays which includes guidance on genetic testing. Although published in 2014, it was reaffirmed as a clinical report in 2019.



Developmental Milestones and Developmental Targets Resources for Families Learn the Signs. Act Early

The Center for Disease Control (CDC's) "Learn the Signs. Act Early." program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need.

Topic #2: Challenge: Be part of the Conversation

MSRGN & Developmental Delays

For each topic area we will issue a challenge for you to try over the next few months:



Developmental Delays & Genetics Challenge**: Be part of the MSRGN Conversation!

Join us on October 5th at 2pm ET, 1pm CT, noon MT, 11am PT for a workgroup that MSRGN is re-convening of geneticists, primary care providers and families to discuss the **new ACMG guidelines** for whole exome sequencing and what impact those guidelines have on the current MSRGN Developmental Delay Algorithm for Primary Care Providers.

If you would like to take this challenge to be part of this MSRGN conversation, please **email Kristi** for the zoom invite.

**Please note participation in this call is not a required activity of the Time 4 Genetics Initiative but rather a challenge to get involved further in this conversation at the primary care level. We would love your input if you can join us!

Don't Forget! Data from Topic #1 is DUE NOW!

Please **email Kristi** any zip codes **(download tool here)** of those patients with whom you utilize any of the Time 4 Genetics information, resources, and tools!

Download the Zip Code
Collection Tool Here



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Mountain States Regional Genetics Network www.MountainStatesGenetics.org







Time 4 Genetics Projects Manager: Kristi Wees kwees@mountainstatesgenetics.org