Important Information for Your Family

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The information included here is important for your family because your baby was born with a health condition that we track in Minnesota. We hope the information in this packet will answer your questions so your family can grow and thrive!

Who we are

The Children and Youth with Special Health Needs program of the Minnesota Department of Health (MDH) works to provide positive health outcomes for children and youth who have, or are at risk for, special health needs, and to better serve their families.

For more information about the section, please visit: www.health.state.mn.us/people/childrenyouth/cyshn.

The health conditions we track

We keep track of certain conditions that babies can be born with. Sometimes these conditions are minor, but many are very serious. It is possible for babies to be born with more than one of these conditions. See a full list of the conditions we track in the insert of this packet.

Why we track these conditions and what information is kept

We keep this information so we can watch for trends or high numbers that might be a concern. These patterns can help us identify causes and prevent these conditions for future births.

The information in the database is carefully protected. It is not public. We only report information as "aggregate data." This means that all numbers are shown as a group, not individuals. For example, we could report the percentage of babies born with cleft lip in Minnesota during 2017.

The database includes these types of information:

- Date of birth
- Location of birth
- Specific birth condition(s) and how it was diagnosed
- Contact information
- Demographics of mother and baby (like age, race, ethnicity)

How we can use this information:

- Report how many babies were born with a condition and describe patterns and outcomes
- Ask local public health nurses to contact you and help with resources
- Provide resources and other information
- Discuss complicated conditions with medical specialists to accurately report the condition

- Partner with other programs serving children and youth with special health needs at MDH
- Contact you about research opportunities to see if you are interested in being involved
- Collaborate with researchers on approved projects
- Evaluate and improve our program

Removing your information

You do have the option to remove your baby's name and identifying information from our program's database. This is called "opting out." Identifying information includes all names, contact information, and specific date of birth for the mother and baby.

If you choose to remove your child's information from our database, you can get the required opt-out form on our website (www.health.state. mn.us/people/childrenyouth/cyshn). At the left side of the page, click on "Information and Resources for Families" and select the link for the Birth Defects Opt-Out Form.

If you want more information or would like an opt-out form mailed to you, please contact us at health.birthdefects@state.mn.us. If you would like to speak with a nurse at MDH, call toll-free 1-800-728-5420.

Please note, the law protects any information we keep in our database (Minnesota Statute 144.2217). If you would like to know the specific information we keep, please contact us.

Other departments who may also be contacting you

If you live in Minnesota, your local public health department may contact you. This may be a city, county, or tribal health department. They can connect you to resources to help your family now and as your baby grows. Your local public health department can answer questions you have related to financial help, child development, and more.

Other programs in MDH like Early Hearing Detection and Intervention may also contact you if your baby has another condition.

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DEPARTMENT OF HEALTH

Children and Youth with Special Health Needs Section

www.health.state.mn.us/people/childrenyouth/cyshn

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To obtain this information in a different format, call 651-201-3650. Printed on recycled paper.