



MSRGN Genetic Navigators Scope of Navigator's Role

A. Navigate with **professionalism and ethics**.

1. Adhere to ethical limits to confidentiality.
2. Refer families to seek the services of geneticists, genetic counselors, pediatricians, nurses, social workers, other doctors and specialists when needed navigation is outside GN scope.
3. Help families understand right to privacy and confidentiality.
4. Help families understand consent to release documents.
5. Understand the professionalism and culture of supporting MSRGN as an organization and our federal funders.
6. Seek and learn from supervision of MSRGN projects manager and staff.
7. Model leadership skills.
8. Provide navigation services in a culturally aware manner.
9. Use person-first language where applicable.
10. Recognize how personal values, beliefs and biases may affect an individual's view of genetics and genetic services, and honor that viewpoint.
11. Create and maintain timely and accurate documentation (google sheets).
12. Be cautious to never offer medical advice or make or advise for/against a medical (or otherwise) decision for a family. All decisions for their child or loved one are the family's decision alone.

B. **Outreach and engage families who need to navigate genetics in their state.**

1. Focus on the family, their strengths and preferences, and right to self-determination.
2. Demonstrate a willingness to appreciate the values and life experiences of families.
3. Utilize lived experience with your own child and family to empathize, support and connect with the family.
4. Strategically share your own family's story (when appropriate and to the extent comfortable).
5. Collaborate with families to identify barriers to genetics care.
6. Partner with families to identify and prioritize family needs throughout outreach and navigation.
7. Help families prioritize/re-prioritize next steps.
8. Share best practices, tips, resources, and self-care techniques that have assisted in own family's genetics journey, realizing that what has worked for our own family may not always be the best fit for another family.
9. Participate in at least 1-2 outreach activities (virtual or in-person) such as a genetics pop-up to reach new families.

C. Guide families as they navigate the genetics system in their state.

1. Share skills with families to advocate for their themselves and their family.
2. Guide families to collaborate with providers in making decisions about their child's care (shared decision making).
3. Assist in facilitating conversations by the family with their primary care provider about genetics, maintaining a focus on the medical home model of care.
4. Support the family to gain access to genetics services and testing where appropriate.
5. Navigate in a manner that assists families in maintaining and building hope.
6. Share personal experiences of the role that hope has played in own family experience.
7. Assist families in identifying their own experience and how it has impacted their hopes for the future.
8. Assist families to fully participate in meetings and appointments sharing their input, concerns and questions with their provider.
9. Understand the grief process and the family's possible emotional responses to a diagnosis.
10. Provide resources to families who may experience conflict on their genetics journey:
 - a. Help families generate options to navigate to what they believe is best for their child or loved one when conflict arises.
 - b. Share resources with families about grievance procedure options in institutions/agencies.

D. Assist in identifying and providing national, regional, state and local genetic resources for families.

1. Serve as an active member of the MSRGN state team, networking with other members and sharing barriers with the team, gathering state resources as part of this group.
2. Advocate for the family voice with other agencies, providers, and professionals in your state.
3. Help families reduce isolation and expand their natural and formal support networks through local, state, regional and national resources.
4. Refer families to appropriate information and services in their state and nationally.
5. Follow up and monitor outcomes of referrals via google sheets documentation of resources.
6. Network with the MSRGN Projects Manager and Genetic Navigators to identify additional resources and practice creative problem solving.
7. Know how to research qualifications for state and federal pediatric insurance plans.
 - a. Be aware of special services and qualifications of families to access those services.
 - b. Provide application navigation and connection to state resources that can assist family in completing application (F2FHIC, social workers, community health workers).
8. Identify techniques and resources that promote good self-care for families and for the navigator themselves.

E. Nurture advocacy and growth of family leaders (with-in the family, community, state or nationally).

1. Facilitate connections of families to family-to-family support groups (locally, statewide and nationally).
2. Identify and share with families opportunities for leadership growth and advocacy training opportunities (through local, state, MSRGN or NGEFSC).
3. Guide families to advocate for themselves and their families in the community and at state and national levels.

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