

Anencephaly the rare neural tube defect navigating the challenges, embracing the possibilities.

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Introduction

Anencephaly is a rare and devastating birth defect that affects the development of the brain and skull. It is a type of Neural Tube Defect (NTD) that occurs during early pregnancy when the neural tube, which eventually forms the baby's brain and spinal cord, fails to close properly. In cases of anencephaly, the upper part of the neural tube does not close, leading to the absence of a major portion of the brain, skull, and scalp. Babies born with anencephaly typically have an underdeveloped or missing forebrain, including the cerebrum, which is responsible for cognition, sensory perception, and voluntary motor functions [1].

Due to the severe nature of the condition, infants with anencephaly are usually born without a complete skull, exposing the brain tissue. Consequently, their life expectancy is extremely limited, and most affected babies are stillborn or die shortly after birth. The condition is often detected during routine prenatal ultrasounds or diagnosed shortly after birth based on physical characteristics. The exact cause of anencephaly is not fully understood, but it is believed to be a combination of genetic and environmental factors. Research suggests that a lack of folic acid, a B vitamin, in the mother's diet before and during early pregnancy may contribute to the development of neural tube defects, including anencephaly [2].

The diagnosis of anencephaly can be devastating for parents, and they often face difficult decisions regarding the continuation of the pregnancy. Supportive care and counseling are crucial during this challenging time to help families cope with their emotions and make informed decisions. While anencephaly is not a curable condition, medical advancements and improvements in prenatal care have allowed for early detection and support for affected families. On-going research focuses on understanding the causes of anencephaly and developing potential preventive measures. Raising awareness about anencephaly is vital to promote understanding, support affected families, and advocate for further research into prevention and treatment options. By sharing knowledge and compassion, we can work towards a future where anencephaly is better understood and ultimately prevented [3].

Anencephaly presents families and caregivers with unique challenges that require strength, resilience, and unwavering support. From the moment of diagnosis to the ongoing care and emotional well-being of those affected, navigating

the complexities of anencephaly can be both daunting and transformative. This section aims to provide guidance, practical advice, and a sense of community to those facing the challenges of anencephaly.

Understanding the diagnosis: Exploring the emotions and reactions upon receiving the diagnosis. Providing information on the medical aspects of anencephaly and its implications. Connecting families with healthcare professionals specializing in anencephaly.

Making informed decisions: Discussing the options available to families, including continuing the pregnancy or considering other alternatives. Providing a safe space for families to discuss their thoughts, concerns, and values. Offering support in navigating the decision-making process.

Creating a supportive network: Connecting families with support groups, online communities, and organizations dedicated to anencephaly. Sharing stories of other families who have faced similar challenges and found comfort in community. Encouraging open communication and the sharing of experiences to foster a sense of belonging [4].

Providing holistic care: Addressing the physical, emotional, and spiritual needs of individuals with anencephaly and their families. Collaborating with healthcare professionals to develop comprehensive care plans tailored to individual circumstances. Exploring complementary therapies and resources that promote well-being and quality of life.

Grief, loss, and healing: Recognizing and validating the grief experienced by families following the loss of a child with anencephaly. Offering guidance on coping mechanisms, bereavement support, and finding meaning in the grieving process. Sharing stories of resilience and hope, highlighting the healing journeys of families who have walked this path.

Advocacy and awareness: Empowering families to become advocates for anencephaly research, funding, and improved healthcare practices. Promoting awareness and understanding within the broader community to reduce stigma and increase support. Participating in campaigns, events, and initiatives that drive positive change for individuals affected by anencephaly.

By navigating the challenges of anencephaly with compassion, education, and a supportive community, families and caregivers can find strength, discover new possibilities, and create meaningful legacies for their loved ones. While the road

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may be difficult, it is through unity and shared experiences that we can transform challenges into opportunities for growth, connection, and hope [5].

Conclusion

Anencephaly let us remember that within the challenges lie opportunities for growth, connection, and empowerment. By coming together as a community, we can provide the support, resources, and love needed to navigate the journey of anencephaly. May we continue to strive for progress, hope, and a future where anencephaly is better understood, prevented, and embraced with empathy and compassion.

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