What Should I Expect During and After the DBS Procedure?

Before surgery

Your child will undergo testing to ensure they are a good candidate for DBS. This might include brain imaging and assessments of movement and motor function.

During surgery

The procedure is done under general anesthesia, and a small device will be implanted in your child's brain. This usually takes several hours.

After surgery

Your child will need a period of recovery. There will be follow-up appointments to adjust the DBS device, monitor progress, and address any concerns.

Ongoing care

DBS requires regular follow-ups to ensure the device is working properly and to make adjustments as needed.

What if I Have More Questions?

Making decisions about DBS is a big step.
It is important to have all the information you need. Consider asking your child's medical team about:

- The details of the surgery and the recovery process
- Support groups or resources for families considering DBS
- Long-term follow-up and how the effectiveness of DBS will be monitored over time
- Your healthcare team can provide more personalized advice, answer your questions, and help guide you through the decision-making process.
- Visit reliable websites dedicated to GNAO1 for trustworthy resources and updates.

GNAO1 ESPAÑA
UN MOTIVO PARA NAVEGAR Y MIL RAZONES PARA SOÑAR

Stichting GNAO NL

Famiglie GNAO1

Aurrera Markelekin GNAO1

The Bow Foundation
supporting GNAO1 families, research and awareness

DBS in *GNAO1-related* disorders

A guide for parents deciding about DBS for their child

SJD Sant Joan de Déu Barcelona · Hospital

European Reference Network
for rare or low prevalence complex diseases
Network Neurological Diseases (ERN-RND)

What Are the Potential Benefits of DBS for My Child?

- **Reduction in symptoms**
  Many children experience a significant reduction in the frequency and severity of dyskinetic crises and dystonia.

- **Improved quality of life**
  Parents report better overall functioning, with children able to participate more in daily activities.

- **Potential for long-term relief**
  DBS may provide ongoing symptom control, especially in cases where traditional treatments have failed.

What Are the Risks or Challenges of DBS?

- **Surgical risks** As with any surgery, there are risks involved, such as infection, bleeding, or complications related to anesthesia.
- **Device-related issues** The DBS device might need adjustments or replacement over time, and there is a small risk of complications, like lead displacement or infection.
- **Emotional and psychological effects**
  Although DBS can improve movement, emotional well-being and cognitive function may still be challenging.
- **Ongoing monitoring** DBS requires regular follow-up appointments to adjust settings and manage the device.

What Do I Need to Consider Before Making a Decision About DBS?

- **Severity of your child's condition**
  DBS is often considered when symptoms are life-threatening or have not responded to other treatments.

- **Other treatment options**
  Consider what other treatments have been tried and their effectiveness. DBS is often used when other options, like medications, have failed.

- **The urgency of the decision**
  DBS can be a life-saving intervention, but it is also a significant decision with both risks and benefits.

- **Support for your family**
  Consider the emotional and practical challenges that DBS may bring to your family, such as the need for ongoing care, device management, and potential side effects.

How Do I Decide if DBS is Right for My Child?

- **Consult with specialists**
  Talk to your child's neurologist and movement disorder specialists to understand whether DBS is a viable option for your child.

- **Assess treatment history**
  Review all the treatments that have been tried and their outcomes. If medications have not helped, DBS may be an alternative.

- **Understand the risks and benefits**
  Weigh the potential improvements in movement and quality of life against the risks associated with surgery and device management.

- **Consider the timing of the decision**
  DBS may be a last-resort treatment, often considered when other options have been exhausted. Discuss the urgency of surgery with your medical team.