

FREDERICK'S GROWTH FUND

321-829 NPO



Supporting Access to the First Ever Pharmaceutical Treatment for Achondroplasia

About the Organisation

Frederick's Growth Fund is a South African Non-Profit Organisation (321-829 NPO) established to serve as a central information and fundraising hub for children with Achondroplasia to gain access to the first ever pharmaceutical treatment of the rare genetic condition. Our purpose is to:

- Increase awareness of the condition and treatment options
- Provide reliable resources for families and caregivers
- Mobilise funding to enable access to approved pharmaceutical treatment
- Advocate for equitable access in South Africa

The organisation also provides a Parent's Information Sheet and resources available at www.fgfnpo.org

The Condition: Achondroplasia

Achondroplasia is the most common form of dwarfism, a rare genetic skeletal condition affecting bone growth which may lead to:

- Disproportionate short stature
- Spinal stenosis
- Foramen magnum compression
- Recurrent ear infections
- Sleep apnoea
- Orthopaedic complications

Ongoing multidisciplinary monitoring is often required throughout childhood.

Treatment Landscape: A Medical First

For the first time in medical history, there are targeted pharmaceutical treatments addressing the underlying growth pathway of Achondroplasia at genetic level.

Approved therapies include:

- **Voxzogo** – Daily subcutaneous injection
First FDA-approved treatment for Achondroplasia (November 2021)
- **Yuviwell** – Weekly injection
FDA-approved treatment (February 2026)

Pipeline therapies include oral tablet formulations currently under development and not yet FDA approved. Ongoing multidisciplinary monitoring is often required throughout childhood.

Treatment Cost

Annual treatment costs remain **in the millions of rands per child**, placing treatment beyond the reach of most families without financial assistance. **Urgent, structured funding support is therefore critical to enable access for eligible children while their window for treatment remains time-sensitive.** Future treatment options and increased market competition may help influence pricing over time.

Children On Treatment vs. Without Treatment

Children Receiving Approved Treatment:

- Improved growth trajectory and skeletal development
- Reduced progression of complications associated with Achondroplasia
- Potential reduction in risk of serious neurological and spinal complications, including spinal stenosis
- Earlier, proactive multidisciplinary intervention and ongoing monitoring
- Improved mobility, independence, and participation in daily life
- Meaningfully improved long-term quality of life outcomes
- Improved emotional wellbeing and mental health through greater physical autonomy, reduced medical burden, and increased social inclusion

Children Without Treatment:

- Progressive growth restriction with cumulative physical impact
- Ongoing risk of serious complications, including spinal and neurological compression
- Increased likelihood of repeated orthopaedic, ENT, and surgical interventions
- Higher lifelong medical burden and frequent hospitalisation
- Reduced functional independence and daily social participation
- Increased psychosocial strain, including challenges to self-esteem, social integration, and mental health
- Overall reduced quality of life trajectory without disease-modifying intervention

Early access to therapy is considered medically significant in optimising outcomes.

Leadership & Governance

Frederick's Growth Fund is led by a team whose work is driven by both professional expertise and personal conviction. Together they bring experience in healthcare, finance, business leadership, and child development, united by a shared mission to improve the lives of children with Achondroplasia.

The organisation is governed by a Board responsible for oversight, accountability, and strategic direction; Bettina Rabiega (Chairperson), Hannetjie Blignaut (Treasurer), Marochelle Botha (Occupational / Medical Advisor) and Chantelle Hall (Founder/Secretary).

Vision

To ensure that children with Achondroplasia in South Africa have equitable access to the first-ever pharmaceutical treatment and the opportunity to reach their full potential.

healthy growth and dignified lives