

Report back: KZN PINSA Social Gathering

Date: 13 August 2023

Venue: Sugar Rush Park, Ballito

Invitation: via KZN PID Community WhatsApp group (admins Tracey Coetsee and Annie Pienaar – 18 group members)

General Comments:

Despite the expression of keen interest from many members of this provincial group, only two families were able to attend the recent social gathering of PINSA members in KZN; totaling 9 guests.

Offers to postpone the event went unanswered, and it was decided to go ahead nonetheless. Unfortunately, some members fell ill, while others opted not to travel to Ballito, as members appear to be spread across the province of KwaZulu-Natal, making it a challenge to get all members together in one venue.

In attendance was the Kruger family from Durban: mom Debbie and father Schalk, with children Jason (15 years), Calleigh Joy (12 years) and Sloan (8 years). Calleigh is currently receiving SCIG therapy and is diagnosed with KBG Syndrome, of which her PID forms part of her many ailments.

The second family were the Powells from Ballito; with mom Melanie and father Jason, to Samuel (10) and Georgina (9). Samuel and Georgina were diagnosed with CVID around 5 years ago, after multiple hospitalisations and misdiagnoses since birth. They received first IVIG therapy for a year before an anaphylactic episode shifted them to SCIG therapy.

The families shared a wonderful lunchtime meal together, as well as the progress, set-backs and various developments in their children's lives.

The Powell family were able to celebrate and share that this was their first successful year off SCIG therapy, marked in June 2023.

The Kruger family shared that Calleigh Joy had been shifted to Cuvitru from Octanorm, and seemed to be suffering from less breakthrough infections since the change. The family also shared their concerns regarding potential growth hormone treatment, and much was discussed about this subsidiary yet important field of additional treatment for some PID children.

It was wonderful that the children were all well and healthy enough to enjoy a game of putt-putt together at the park facilities, (at the parents' expense), while the parents chatted.

A photo was shared to the WhatsApp group, and the suggestion to meet at a more central location next time was floated.

Post-gathering points to note:

- The consensus is that this should be the first of many more KZN talks, gatherings, and support structures to come, and that the KZN group will hopefully grow and become more organized.
- It is noted that future gatherings must also be communicated via the PINSA_Link to be more inclusive.
- Further efforts must be made to ensure all WhatsApp group members are also registered PINSA members.
- More PID patients must be made aware of, and invited to join, the provincial WhatsApp groups for support, encouragement, and additional communications.



From left to right: Georgina, Melanie, Samuel, and Jason Powell, with Sloan, Debbie and Calleigh Joy Kruger.

Not pictured are Schalk and Jason Kruger.