



084-338-NPO

18 May 2019

VENUE: 48 Vredeloof Road, Vredeloof, Brackenfell

TIME: 14H00

The main aim of the Foundation is to provide support to all diagnosed with Cystinosis in South Africa, as well as their families, in order to create a sense of community.

In order to achieve the aim, it is intended that the activities of this FOUNDATION shall include the following:

1. To provide a forum and social network for Cystinotics and their families to share personal experiences and provide sympathetic understanding.
- 2 To provide access to counselling and other support services which can be of assistance in alleviating their difficulties and struggles where possible.
- 3 To ensure that the medical needs of Cystinotics are being timeously and effectively addressed through lobbying and advocacy amongst health professionals.
- 4 To provide education and raise awareness about Cystinosis through information distribution and campaigning.
- 5 To Participate in conferences relevant to Cystinosis in order to stay up to date with information and research related to Cystinosis.

The Cystinosis Foundation South Africa is a Non-Profit, All Volunteer Organisation

AGENDA

1. Welcome and opening remarks Gail Daniels
2. Apologies
3. Moment of silence Gail Daniels
4. Words of Encouragement Charlene Wheeler
5. Opening Prayer Danielle Daniels
6. Minutes of Previous A.G.M Judy Kerrich-Walker
7. Adoption of Minutes
8. Matters Arising from Minutes
9. Presentation of Annual Report Board Members
10. Adoption of Report
11. Presentation of Financial Accounts Colin Daniels
12. Adoption of Accounts
13. Structure
14. Closing remarks Gail Daniels

8. Matter arising from Previous AM

9. Presentation of Annual Reports:

9.1 Chairpersons report

2018-2019 have been both a challenging and rewarding year. The work of the Cystinosis Foundation South Africa will always reflect highs and lows, successes and failures as well as our gains and losses.

Yet, we look back with gratitude to God for His love, wisdom and guidance. We have been blown away with His providence and faithfulness, without him all this will be meaningless.

On behalf of all our families, allow me to express a heartfelt thanks to each and every Board member for your commitment, time and hard work over the last year. Your love and care encourages us beyond measure.

A big thank you to the Bible study groups, our Friends and Supporters who came alongside and partnered with us in various projects and fundraisers. Without your support and prayers we would not have been able to reach our goals.

We are also delighted to welcome our two new members, Elsabe Veldtman and Charlene Wheeler, to our Board. Thank you for your willingness to serve and share your gifts and talents for the benefit of the cystinosis community. I am confident that your contribution will add value to our work and that you may continue to grow in your faith.

Finally, we bid farewell to two of our members; Margie Jack and Myrna Schafer as they retired from our Board. Thank you so much for the blessing of serving with you. Your contribution towards the work of the Cystinosis Foundation will long outlive you. You have both done an incredible job! Continue to serve the Lord with joy and gladness! God bless.

9.2 New Families

In December 2018 the Karaan family has been added to our community. Two of their children, Gasant, age 12 years and Gadija, age 2 years were both diagnosed at Red Cross Children's Hospital. The family lives in the Strand, Cape Town.

9.3 Support to Families

- ◆ Emotional and Spiritual support:

9 of our children are currently in chronic kidney failure and is battling with the daily challenges thereof. This leaves our families with many questions, fears and anxiety. We assisted with education with regard to kidney failure as well as spiritual encouragement and prayers.

The loss of Kagiso Mdumata has also been a shock to our community. Once again we encouraged them to find comfort in Scripture and in God's sovereignty.

- ◆ Intervention:

One of our functions is to intervene between Doctors and parent when needed. In most cases it is to clarify diagnoses, results and terminology. In the past year we have also been contacted to speak to families with regards to compliance.

- ◆ Medication:

We ensure that the treatment is delivered on time, especially to patients living outside of Cape Town.

- ◆ Financial support:

2x Food vouchers to the value of R1000.00 each

Funeral assistance to Olwethu of R1000.00

Assistance with transport to our Annual Family Gathering.

9.4 Fundraising and Events

9.4.1 Games Night –Judy Kerrich-Walker

One of annual fund raisers – the Games Evening, was held at Emmanuel Church on the 28th July at 5 pm.

Tickets cost R50 for adults and R20 for scholars and brought in a total of R3553.

Alan Anderton was again our Games Master, and we served hamburgers and soup with brownies for pudding. Coffee, tea and Coke were served. Peninsula Beverages again kindly donated the Coke. Food sales raised R2040.

Gail gave a talk, informing those present (about 70 people – not as many as we had hoped for) about our families, and the slides of our families were running in the background during the evening

This year, we had a Voetstoots table for the first time, using items donated from various friends. This raised just over R7000. Most of the leftover goods were donated to the Bellville Hospice.

We had a "lucky draw" with 4 "happy snack boxes" as prizes, as well as crowns and Smarties for the winning team (the Smart ones!)

Security in the Foyer was much better this year, thanks to Colin, and our profits (after expenses of R1506) was R10331, all of which was passed directly on to our families in the form of a Shoprite voucher for R1000 per family. The Board decided to put in the extra amount needed from monies previously donated.

9.4.2 Annual Family Gathering—Jenny Brigden

THE HIGHLIGHT OF OUR YEAR

It is with great excitement that the Board get together every year to plan our annual Family Gathering. We really try to spoil our families as they make a lot of effort to attend. We had 13 families attend out of 19 families that we have.

We welcomed them with eats and drinks and allow them to greet those that they have been in contact with during the year via Whatsapp. It is heart-warming to see the friendships that have formed.

The children were entertained while the parents had a Session with Gail. Everyone was welcomed and a devotion and prayer said by Rose Stevens. We remembered Stefan Adonis who sadly passed away in May at the age of 20 years.

Gail shared with the parents a DVD she had taken from the International Conference that she attended in Berlin, Germany in July 2018. The report on the conference was a great encouragement to our parents to see that there were a lot of graduates and even a marriage. The oldest Cystinosis patient is 55 years from UK. The message that came across was that these children/adults could lead relatively normal lives if they just comply, comply, comply.

We then had our own panel: Danielle, 25, who is running her own coffee shop, Sibonile, 19, who

completed matric last year and is studying Management through Unisa and Tarique who matriculated this year (2018) and is still applying at colleges and varsity for I.T. Studies. They were questioned and once again the importance of compliance was highlighted. The one thing they would all change is the taste of the Cysteamine. Dr Buisson, the paediatric nephrologist, from Tygerberg Hospital, agreed with them and said they are working on trying to get it into capsule form. These sessions are a real encouragement for the moms who can share their struggles as they are the ones who are living with them.

The children then joined everyone and Gail then welcomed any guests and friends that had joined us.

The children all received a special reward from Lucy (The various Bible Study Groups and friends had up love boxes). Myrna then awarded the Empatheia award to Ouma and her husband in her best Afrikaans to thank “Ouma” Sarie and Mr Draai for the love, care and devotion that they gave to Stefan. The Draai’s have fostered 10 other children over time. The Empatheia award is given to those who have lost a child in the year so they know we feel their pain and will not forget them.

Dane then handed over the Macedonian award to Beyonce Prinsloo. The Macedonian award was Dane’s idea borne out of the idea to help a child that is struggling at school because of monetary restraints.

A prayer and grace was then said and we retired to the hall which is always beautifully decorated by Rose Fortuin, for our special lunch. Gammon, silverside, chicken, bean, pasta and a green salad followed by trifle and ice cream with sprinkles. Father Christmas was then called and arrived with a huge bag of toys for the children. Always great excitement to see the anticipation in the little one's faces. Father Christmas also gave the parents a box of biscuits and a voucher which we hope will help them through the Christmas season. The helpers were also given a gift to show our appreciation of their help.

The day ended with a piece of cake and takeaways for our families who had a long way to return home with tired little ones. Our faithful "lifters" then took the families back to Cape Gate where they get on taxis and go back to their homes. How does one sum up this joyous occasion? We can only thank God for His faithful provision and are thankful that He is in control.

9.4.3 The High Tea—Elsabe Veldtman

Our annual high tea was held on 2 March 2019 at Emmanuel church in Amanda Glen. Our new venue was generously sponsored by the church and allowed us to join our morning and afternoon groups in one session. It was the first time we were able to host all our Cystinosis "tea loving" friends in one venue.

The theme for this year was "Something Rare" in celebration of Rare Disease day. Patrons were encouraged to wear something rare and they did not disappoint! We also had face painters to cater for those who felt adventurous.

The event was well attended and our friends once again blessed us with their generosity. We had fewer auction items as our regular sponsors were unable to donate items to auction. This however allowed us to find a fun and creative way to raise funds. We were blessed with many items for our "voetstoots" (second hand) sale table and introduced a pop a balloon game which allowed everyone to give generously and walk away with a fun surprise gift.

We also showed a short video clip on Cystinosis which was very educational and well received by our friends.

A total amount of approximately R22 000.00 was raised which will be used toward for our year end function (Annual Family Gathering).

Over all our day was very successful as it yielded many smiles, well fed patrons and a new group of friends who learnt more about Cystinosis.

9.5 International Conference 2018—Gail Daniels

Danielle and I were once again privileged to attend the International conference in Berlin Germany. The conference was organized by the Cystinosis Network Europe. There 200 participants, a jammed packed programme with many presentations from the experts and researches in the field. The conference also allows a few social activities which give us the opportunity to meet some old and new friends.

The following information gathered at the conferences is extremely helpful:

- ◆ Research for improved drugs is continuous. It was found that Cysteamine does not improve all cell systems. Genistein, a drug available in health shops, has been found to reduce cystine levels and improve kidney function.
 - ◆ Ophthalmology: The crystals on the cornea can be reversed with strict compliance of the eyedrops. This is very good news and should be encouraged.
 - ◆ The Neurological effects of cystinosis is a huge concern. The following is therefore of great value.
 - ⇒ Cystine storage in the brain
 - ⇒ Vasculopathy (affecting blood vessels and can cause infection) in brain
 - ⇒ Cerebral atrophy and central volume loss (brain is literally getting smaller)
 - ⇒ Dystrophic calcification (in soft tissue)
 - ⇒ Neurocognition impairment—trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. This already apparent in some young children
 - ⇒ Intelligence normal range (low level)
 - ⇒ Visual special difficulty
 - ⇒ Visual memory
 - ⇒ Behavioural problems: social problems, Attention deficit, anxiety and depression, delinquent aggression and internalization.
 - ⇒ Muscle weakness & wasting: Mainly hands and lower limbs affected, causes deformation, smaller frame and claw hands
 - ⇒ Respiratory muscle can be affected: Respiratory weakness, more frequent infection, pulmonary insufficiency (Life threatening)
- Other: Swallowing, slow eating, seizures and strokes
Conclusion: Higher prevalence of neurological effects manifest as patient gets older
Important: Compliance of cysteamine improve neurological symptoms.
Encourage exercise, an active and social life and a positive attitude.

The CNE has also invited me to join them as South Africa's representative. This will keep us abreast with ongoing research and information about cystinosis.

Next month, Luke McDowd (Dublin, Ireland) an 18 year old with cystinosis, will be travelling to South Africa with his school to play rugby. His Mom, Anne-Marie has asked me to be his contact person should he need any medical emergency.

Thank you to the board for making this trip possible!

9.6 Raising Awareness—Gail Daniels

One of our chief aims is to raise awareness amongst the public and medical professionals. Thus it is important to use every opportunity especially when children are hospitalized.

Family Clinics

We distributed information to all Clicks Pharmacy family clinics and is currently in contact with the Western Cape Health department to do the same at all Family Clinics within the Metropole.

Schools

During Rare Disease week we've had the opportunity to address 500 learners of Protea Heights Academy. We were encouraged by the interesting questions and their desire to know more. Once again we distributed flyers and booklets to the Educators.

Fundraising Events

Our fundraising events are wonderful opportunities to raise awareness by means of presentations and an information table.

Coffee Perks

Danielle's Coffee shop has created many opportunities to share with various groups, they often request a short talk on cystinosis. Pamphlets and brochures are on display for those who are keen to know more or share the information with others.

Bellville Rotary

Colin and I were invited to The Bellville Rotary Club where we were recognized with a Community Service award for the work done within the cystinosis community. This created a wonderful opportunity to raise awareness to the Rotary leaders across the Western Cape. An article was published in the Tygerburger.

9.7 Celebrations

In the midst of living with the daily challenges of cystinosis it is encouraging to receive good news of our children's achievements.

We want to congratulate Tarique Kenny for successfully completing Matric and pursuing his dreams.

Well done to Sibonile Yose who completed a 2 year correspondence course in Business Management through Unisa in 1 year. Sibonile continues to show fortitude despite the many complications of dialysis and frequent hospitalization.

Coffee Perks has been a dream come true for Danielle Daniels. After her kidney transplant she has renewed energy to do what she loves. We are happy for her and wish her well with her coffee shop.

These 3 young adults are a great example and encouragement to our families with younger children. They have made us all proud and we wish them well in all their endeavours.