



084-338-NPO

27 June 2020

**Virtual AGM via Zoom
TIME: 10H00**

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. Words of Encouragement Judy Kerrich-Walker
4. Opening Prayer Lynn Reebein
5. Minutes of Previous A.G.M Judy Kerrich-Walker
6. Adoption of Minutes
7. Matters Arising from Minutes
8. Presentation of Annual Report Board Members
9. Adoption of Report
10. Presentation of Financial Accounts Colin Daniels
11. Adoption of Accounts
12. Structure
13. Closing remarks Gail Daniels
14. Closing Prayer Liz Lombard

**6. MINUTES OF THE ANNUAL GENERAL MEETING OF THE
CYSTINOSIS FOUNDATION SOUTH AFRICA
HELD 48 VREDEKLOOF ROAD, VREDEKLOOF
ON 9TH MAY 2019 AT 1400 hours**

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 of Board
14. Closing remarks - Gail Daniels

WELCOME AND THANKS

Gail welcomed all those present (Liz Lombard, Lynn Reebein, Jenny Brigden, Judy Kerrich-Walker, Colin and Gail Daniels, Danielle Daniels and Charlene Wheeler), and expressed her thanks to all who had contributed to the work of the Foundation in the last year.

2. APOLOGIES

Sandi Potter, Elsebe Veldtman

3. KAGISO MDUMATA

The meeting held a moment of silence for one of our Cystinosis children, Kagiso who had died In March 2019

4. WORDS OF ENCOURAGEMENT

Charlene Wheeler gave a word of encouragement from 1 Peter 4:10-11, stressing that The Lord has given us all different gifts and we can use them with confidence as we serve the Cystinosis Foundation and our families, in order that others may flourish. Whatever our gifts may be, we must serve with excellence so that God is glorified through our actions.

5. PRAYER

Danielle Daniels opened the meeting in prayer, including prayer for Kagiso's family (Olwethu and Afrika)

6. MINUTES OF THE PREVIOUS AGM (2018)

These were read by Judy Kerrich-Walker.

Corrections: 1. Date corrected to 2018, not 2017

2. The Financial statements are not audited, but are examined and scrutinized by an accounting officer.

7. ADOPTION OF MINUTES

The minutes were accepted as an accurate account of what had transpired at the meeting.

Proposed: Liz Lombard

Seconded: Jenny Brigden

8. MATTERS ARISING FROM THE MINUTES

Nil

9. PRESENTATION OF ANNUAL REPORT

The Annual Report was presented by the Chairman and various Board members:

9.1 Chairperson's 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 need ed. 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 Beyoncé 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.

9.4.3 The High Tea: - Elsebe 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 “voetstoets” (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 eye drops. 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 shop has created many opportunities to share with various groups, they often request a short talk on 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' 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 they endeavours.

10. ADOPTION OF ANNUAL REPORT

Proposed: Danielle Daniels

Seconded: Lynn Reebein

11. PRESENTATION OF ACCOUNTS (see attached)

Colin Daniels presented the Financial Statements and gave the following comments

1. Thanks to God for what He has achieved
2. Thanks to the Board for the fund raising efforts
3. The accountant was happy with the finances, with money being paid in and also being used for the running of the Foundation and for our families, as well as money being correctly allocated and income increasing.
4. Fixed assets are the computer and PA system which were bought in the last year. Other fixed assets had been bought previously to the present financial statements
5. The income from 2018 was higher than for the present year because of the closure of the Capitec account and these monies being paid into the ABSA account
6. Expenses for the current year had increased because of the costs of the International Conference in July 2018
7. The accountant had approved the suggestion to take a large portion of our money and invest it in a high interest account and one which would not require a lengthy notice of withdrawal. The Board all agreed that the Treasurer and Charlene Wheeler should investigate the options available, and a decision as to the institution and the amount invested would be decided at the next Board meeting

The Board thanked the Treasurer for his hard work in the running of the financial affairs of the Foundation

12. ADOPTION OF THE ACCOUNTS

The Financial Statements were taken as true and correct.

Proposed: Charlene Wheeler

Seconded: Liz Lombard

13. STRUCTURE OF BOARD

Letters of resignation had been received from Myrna Schafer and Margie Jack.

Charlene Wheeler and Elsebe Veldtman had joined the Board

Otherwise, the Board remains the same

14. CLOSING REMARKS

Gail Daniels thanked all for attending and encouraged everyone to work zealously in the coming year!

There being no further business, the meeting was closed in prayer by Judy Kerrich-Walker

Tea and refreshments were served.

7. Matters arising from Minutes:

11.7 After careful investigation, an amount of R50 000.00 has been invested with Investec through Efficient Wealth Service.

7. Matter arising from Previous AM

8. Presentation of Annual Reports:

8.1 Chairpersons report

The Cystinosis Foundation South Africa is in its 10th year of existence . By God's grace and providence our organisation has continued its work of supporting all families affected with cystinosis in S.A and creating a platform for families to connect and grow as a community. We have seen a steady and significant growth in reaching our goals and establishing an effective organisation. Over the passed 10 years we have supported 29 families of whom we sadly lost 10 children.

We have been blessed with a very capable and committed Board who has served this organization and its community with their gifts, skills, resources and faithful prayers. We are grateful to them for providing consistent and sound governance, always putting the needs of the families first.

Over the past ten years, we have established good relationships, nationally, with hospitals, doctors, pharmacists and administration staff who are directly connected to our community. These relationships are important to assist our families and intervene on their behalf.

We also started a database of the Friends of the Foundation. We are grateful for their partnership, faithful support and prayers. Their commitment and efforts are invaluable to us.

Internationally, we have also established affiliations with Cystinosis Network Europe (CNE) as well as the Cystinosis Foundation U.S. These affiliations are important to stay abreast with the developments of new treatments but also learn more about research in the many affected areas of cystinosis.

Our Treasurer will look at our finances in more detail, but it is encouraging to see how our income has grown over the last couple of years through donations, once-off contributions, and our monthly support from the Cystinosis Support Group Netherlands. We are blown away by God's faithful generosity. With the increased income the board generously increased the Food vouchers to the families to R1000.00

This also enabled the Board to send Gail and Danielle to attend the International Conference in Spain (2016) and in Germany (2018).

8.1 Chairpersons Report /continues . . .

2020 came with an unexpected global pandemic which left our country in lock down, leaving many families destitute; without work and income.

Cystinosis does not take a break during a pandemic. Our children and loved ones are still facing the many challenges living with cystinosis brings and so, amidst this pandemic, they still need to be cared for. Our Board decided, without any hesitation, to use from our available funds to assist the families with an additional R1000. food voucher each, which our families deeply appreciated.

In closing, despite the many challenges this unprecedented event brings, I remain, optimistic and excited about the growing opportunities cystinosis provide to assist, reach out and impact our families; physically, emotionally as well and more importantly, spiritually.

We commit the next 10 years to God, trusting in His wisdom to guide us every step of the way.

8.2 New Families

In December 2019 the Pietersen family has been added to our community. Nicolin, age 3years and his Mom, Brenda, a farm worker, are from a farm outside of Swellendam in the Overberg, Western Cape.

8.3 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.

In December 2019, Sibonile Yose received a kidney transplant at Red Cross Children's Hospital. The family received wonderful support from both the Board members and the cystinosis community during their long stay here.

◆ Intervention:

During the past year, we continue to intervene between Doctors and parent when needed. In most cases it is to clarify diagnoses, results and terminology. We also ensure that treatment is dispense and delivered on time to families living outside of Cape Town. Supporting families with appointment dates and transport arrangements to hospitals.

◆ Financial support:

June 2019 each family received a R1000. food voucher from money raised at Games Night.

Financial support /continues

November 2019, each families received a R1000.00 Food voucher at our Annual Family gathering as well as R 200 per family towards their transport.

The unexpected arrival of the Covid-19 epidemic, left most of our families destitute, especially during the National lock down from 16 March 2020.

The Board decided on assisting each family with an additional Food vouchers to the value of R1000.00 each at the end of April 2020.

8.4 Fundraising and Events

8.4.1 Games Night – Elsebe Feldtman

Our annual games evening has become a firm favourite on our events calendar.

The games evening was held on 27 July 2019 at Christ Church Tygerberg at 5pm.

This is the first time that the event has been moved to a different location.

Tickets were sold at R70 per adult and R30 for students and scholars. A cup of soup and bread was included in the ticket price (The soup was generously donated by various friends). Our ticket sales were up in comparison to the previous year and we also had many guests who attended for the first time.

The event offers a valuable opportunity to create awareness on Cystinosis amongst the guests. Gail played a video clip that explains the disease which was received with much interest. Pamphlets were also made available to those interested in learning more.

The quiz game requires entries of teams consisting of 8 – 10 participants who battle it out by answering a range of general knowledge questions presented by our quiz master, Alan Anderton.

Teams usually dress up according to a theme of their own choice and our enthusiastic entrants never disappoint when it comes to creativity.

The quiz is usually followed by more relaxing board games for those who would prefer not to be challenged by our quiz master.

A variety of needs are catered for and for this reason the evening included sale of food and drinks as well as a “pop a balloon” game - Participants bought balloons in exchange for a gift.

The ticket also included a cup of soup and bread which was well received by our guests.

The winning team was crowned with prizes for second and third place as well as spot prizes.

Proceeds of all sales including entry tickets and food sales (R13 305.00) were channeled back to our Cystinosis families. Eighteen families received Shoprite vouchers at the value of R1000 each. This brought much needed relief for our families during the winter months.

8.4.2 Annual Family Gathering—Jenny Brigden

THE HIGHLIGHT OF OUR YEAR

Our Annual Family Gathering took place on 29 November 2019.

It is with great excitement that the board get together to plan the annual gathering as we have families that make a tremendous effort to attend from as far as Port Elizabeth and 1 family even leaving George in the early hours of the morning.

We had 16 families attend this year with 2 new families, 1 from the Strand with 2 of their 4 children having Cystinosis and the other from George. It was very touching to see the support given to the new mom who was struggling with her child's diagnosis.

We held our event at the Common Ground Church Hall which is very close to the Red Cross Children's Hospital as we were hoping that because most of the families knew where it was that they would be able to arrive on time. We welcomed them with coke, watermelon and fruit kebabs.

Judy opened with a devotion and prayer and we remembered little Kagiso who passed away in February. The children were entertained by the youth of Christ Church Tygerberg, while the parents had a question and answer session. It was very heart-warming to see the love and support shared by the families.

Myrna handed out the Empatheia award (It is given to the parents who has lost a child so they know we feel their pain and will not forget their children) and prayed for Olwethu, Kagiso's Mom. Dr Mignon was able to join and brought a colleague from Kenya along. She handed out parcels to all the children. Dane then awarded the Macedonian Education Award to Sibulele Kelemba (Grade 9 Leaner)

The Macedonian award was Dane's idea to help a child who is struggling at school because of monetary restraints.

A prayer and grace was said and we ate our "picnic box" lunch sitting around in groups. As Father Christmas was very busy this year "Mary Christmas" arrived to distribute the gifts to the children which they received with great excitement! As our children are much older most of them received a voucher to go and choose their own present. Mary Christmas also gave the parents a tin of biscuits and a voucher which we hope will be a help over the Christmas season. The helpers were also given a gift to show our appreciation of their help.

The day ended with an ice cream and lifts back to Red Cross.

We once again thank God for his faithful provision and praise him for his goodness that never ends.

8.4.3 The High Tea—Charlene Wheeler

On Saturday 29th February 2020 we celebrated the 10th Anniversary of Cystinosis Foundation SA and Annual High Tea. The event was held at Emmanuel Church in Amanda Glen, Durbanville and this was the 2nd year that they sponsored the use of their church facility for our celebrations.

To celebrate this auspicious occasion and in keeping in line with the colours of Cystinosis Foundation SA, all board members wore sky blue tops and white slacks/skirts and our guest were encouraged to wear blue and silver with a touch of bling.

This year each of our 16 hostesses not only hosted a table but they also provided all the crockery and cutlery items for their specific table/s which not only added to the fun and excitement but was a wonderful opportunity for hostesses to be creative with their table/s settings.

The afternoon was jammed packed with presentations, entertainment, an auction, pop the balloon prize game and of course treating our 160 guest to a delicious cup of tea and sweet and savoury treats.

Some of the highlights of the High Tea was a presentation done by Dr du Buisson where she emphasised the importance of a support group for chronically ill Cystinosis patients. Guest were also entertained with a beautiful song item by Davine, the sister of a Cystinosis patient.

Last but not least our guest actively participated in the auction and pop a balloon game and we are grateful for their generous donations whether cash or kind. The High Tea raised a total of R25060.00 which assisted greatly to achieving our goal of raising much needed funds for our year end Annual Family Gathering for all Cystinosis children and their immediate families

The High Tea was certainly a joyful and fun filled occasion and a celebration of God's faithfulness towards Cystinosis Foundation SA for the past 10 years and it allowed an opportunity to create ongoing awareness of Cystinosis.

Positive feedback received from those who attended the High Tea definitely yielded new friends and support for the organisation.

8.5 International Conference 2020—Gail Daniels

The International Cystinosis Conference was due to take place in Dublin in July 2020. It was cancelled due to the COVID-19 risks to our families but we felt that the cystinosis community still needed to have this conference to take place. It is easy to feel isolated and disconnected during this time and the conference will show us that our doctors and researchers are still working for us and we are here ourselves as a global community.

It was thus decided that the International Conference will go On-line on 25th April 2020, a first for the global cystinosis community. The Virtual Conference hosted; 8 languages – 15 speakers – 20 time zones – 49 countries – 900 registered attendees! A truly extraordinary event!!!

It was in laypersons terms with live translation.

We were able to watch cystinosis world experts (with translation) presenting the latest information on managing cystinosis; educational issues; bones and muscles; eyes and possible new treatment; kidneys – pre-and post-transplant and keeping well; the latest research in gene therapy and new treatments; pregnancy and male fertility; the impact of COVID-19; and maintaining your mental health. Informal chat rooms on particular topics were also available.

Speakers included Prof Elena Levtchenko (Chair), Dr Atif Awan, Dr Rachel Bishop, Prof Don Cairns, Dr Anuj Chauhan, Dr Stephanie Cherqui, Prof Paul Goodyer, Prof Paul Grimm, Dr Patrick Harrison, Prof Craig Langman, Dr Herbie Newell, Dr Joyce Senior, and more.

The On-line Conference made it possible for many, who would not normally attend, to participate. I am very grateful for our Board members who joined in and in so doing learned more of cystinosis and our community.

8.6 Raising Awareness—Gail Daniels

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

Tygerberg Academic Hospital:

During the hospitalization of Nicolín and Intando, we held discussions with medical students and were able to hand out information booklets and flyers.

Fundraising Events

Our fundraising events draws many new and interested people to our community who wants to know more about cystinosis. It therefore presents wonderful opportunities to raise awareness by means of presentations and an information table.

Coffee Perks

Danielle's Coffee shop continues to create many opportunities to share with various groups, talks on cystinosis. Pamphlets and brochures are on display for those who are keen to know more or share the information with others.

8.7 Celebrations

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

We want to congratulate Tarique Kenny for pursuing his (3years) undergrad s studies, Bachelor of Arts (BA) in Communication Science through UNISA.

We rejoice with Sibonile Yose and her Mom, Phindiwe for her successful kidney transplant. Sibonile is currently enjoying good health and is continuing her studies with UNISA.

Intando received a feeding machine with Dr Christelle Du Buisson efforts at Tygerberg hospital. This has made a tremendous difference in his well being. He is gaining weight and becoming stronger.

Nicolin (age 3years) are making strides as he started crawling a few weeks ago. This is a great milestone in his development.

These are just a few examples of the endless things we are grateful for. Our children are our heroes who everyday of their lives battle with the realities of this devastating disease and therefore everyday is a celebration of God's grace and faithfulness to them and their families.

9. Adoption of Reports:
10. Presentation of Financial Report: Colin Daniels
See attached.
11. Adoption of Financial Account / Report:
12. Current Structure:

Chairperson	Gail Daniels
Secretary	Judy Kerrich-Walker
Treasurer	Colin Daniels
Assist. Treasurer	Liz Lombard
Patient Rep	Danielle Daniels
Hospital Support	Lynn Reebein
Board Member	Elsabe Feltdman
Board member	Jenny Brigden
Board member	Charlene Wheeler
Additional Member	Sandi Potter

Medical Advisor	Dr. Mignon McCullough (Red Cross Children's Hospital)
Medical Advisor	Dr. Christelle Du Buisson (Tygerberg Academic Hospital)

13. Closing remarks

*'We live in a world in which we need to share responsibility.
It's easy to say It's not my child,
not my community,
not my world,
not my problem.
Then there are those who see the need and respond.
I consider those people my heroes.'* - Fred Rogers

Thank you so much to each Board member, Friend and supporter, for your commitment and enthusiasm to making a difference in the world of our cystinosis community. Your love, care, support and prayers might seem a small and insignificant contribution but means everything to our families.

May we continue to shine the light of the gospel as we continue to serve this community for the following 10 years;

14. Closing Prayer:

Liz Lombard