SACFA ANNUAL GENERAL MEETING 2024

As long as you're breathing, it's never too late to do some good.

REC

*Please note that this meeting will be recorded.





Agenda

01	WELCOME - KIM
02	CHAIRMAN'S REPORT - KIM - 10MIN
03	FINACES - HEIKE - 5MIN
04	STRATEGY FOR STATE PATIENTS - DR ZAMPOLI - 15MIN
05	EMPOWER THE PATIENT - RIDA - 15MIN
06	CLINIC PARENT - ANNAMAIRE - 5MIN
07	ELECTIONS OF MANAGEMENT COMMITTEE - KIM - 5MIN
08	QUESTIONS & COMMENTS



Welcome

- Please keep your mic on mute.
- This is being recorded.
- A summary of this meeting will be emailed

Chairman’s Report

Kimberly Keyzer - Chairman

Hosted a strategy session facilitated by RDSA Process of creating a more structure

Our objectives include communicating with the CF community, raising public awareness and promoting medical advancements. Fundraising is essential to sustain these objectives.



Achievements

- Established partnerships - RDSA, WPA, IPASA, and Breathtaking Fundraising
- Aiding patients by providing them access to medication, guidance, or financial support.
- Funding the SA CF Registry
  2023 data report will be released 2025
- Fundraiser events 2024
  1. CF Genes Day - 31st May
  2. Virtual 6.5 - Sep
  3. Golf Day - 12th Nov

Fundraisers 2024

This year we held several fundraisers, from online events to an in-person golf day.
These funds go towards:

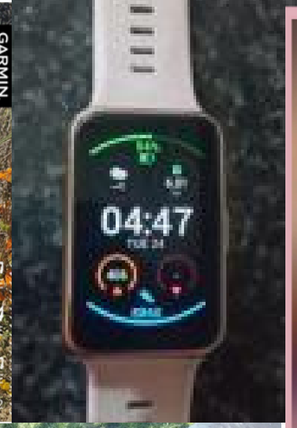
- Assisting CF warriors
- Paying for a social worker and a dietician at the Paediatric Charlotte Mekke Johannesburg hospital.
- Making them a multidisciplinary team.
- SACFA Registry.
- A Patient Empowerment Team and Focus
- Welcome packs to new parents and patients.
- State clinic support (food, parcels, and vitamins)

We want to thank each and every one of our supporters, donors, doctors, patients and parents who have helped SACFA grow this year.

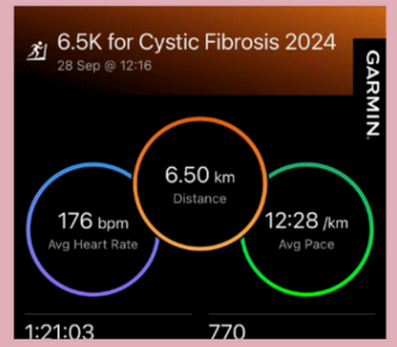






















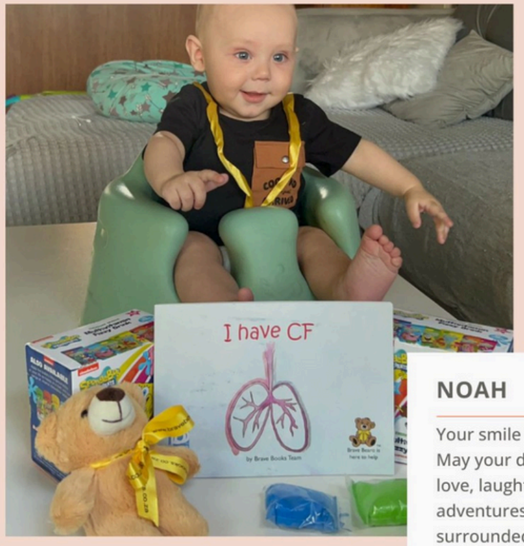








South Africa Association

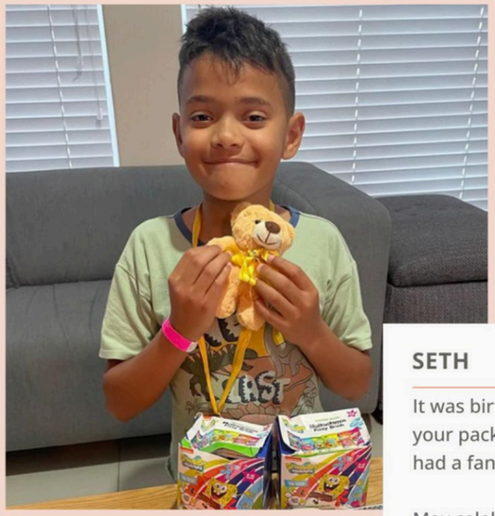


MEET *Noah*

NOAH

Your smile lights up the world! May your days be filled with love, laughter, and endless adventures. You are surrounded by so much warmth— never forget how deeply you are cherished.

www.sacfa.org.za



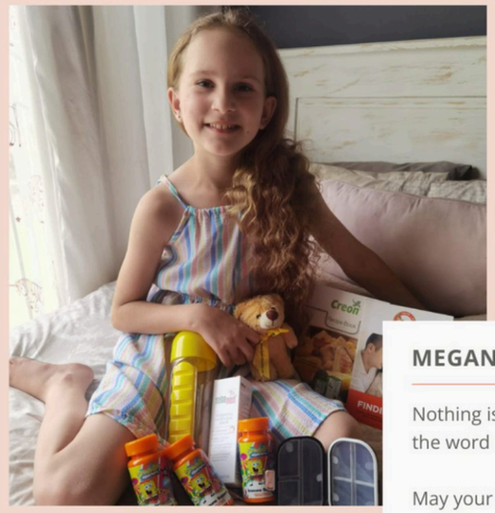
MEET *Seth*

SETH

It was birthday when I sent your package. I hope you had a fantastic celebration!

May celebration be your attitude, unconditional of what life brings.

www.sacfa.org.za



MEET *Megan*

MEGAN

Nothing is impossible. Even the word says I'm possible.

May your days be filled with countless hours of possibilities

www.sacfa.org.za

South Africa Association

Future Plans

- Access to the care and support needed to thrive

- **Focus on**
  1. Expanding patient support programmes,
  2. Advocating for equitable access to medication
  3. Increasing public awareness





STRATEGIC GOALS

01 Access to Multidisciplinary Team (MDT)

- What do we consider a Multidisciplinary Team?
- Assess where clinics are and are they serviced by a MDT?

02 Diagnosis

- Map out patient journey to indicate the pressure points where diagnostic referrals happen
- Develop IEM for primary health promotion

03 Medicine Access

- Update CF consensus document, including societal issues
- Call to Action for funders (gov & pvt) to adopt protocals

2025 Fundraisers

Name of Project	Description	Date of Event	Current Status	Responsible Person
CF T Shirts	SACFA t shirts	Year round	Still stock - only 2 Large shirts left	Kim K
CF Awareness Month	Public awareness via social media and other media	May 2025	Social media to be a major aspect of this project.	Jolene P and Kim K
CF Genes Day	Fund-raising Sticker sales	28 May Wednesday	• Sale of stickers • Schools • Corporate	Kim K
6.5km run, walk, cycle or swim	Virtual 6.5km event	May 2025	• Annual event • Based on 65 Roses	Jolene P and KK
CTCT 2025	Sponsorship/ fundraising/ awareness	9th March 2025	• Enter team (AD) • Flyer (AD) • Monthly reminder (JP)	Alan D
Golf Day (JHB)	Randpark Golf Club	November	• Venue to be booked (paid) • Target is 30x4 balls • Auction items required • Prizes required • Marketing of event (JP)	Alan D/ Anita T

Volunteer opportunities

Your time and skills are invaluable.

- SACFA Committee Secretary
- Fundraising - run a fundraiser
- Guidance on business management
- WA - Watchdog duty
  - An influx of scammers and trolls
  - Review/ validation process implemented
  - Led by volunteer - Leila Poonan
- Clinic Guardian
  - Annemarie will discuss later

Watch dog on WA groups

- Go through the patient communication training to ensure we are communicating a universal message
- Please report any issues you need help with
- Please report any special requests
- You may be asked to the phone the new person to welcome them
- Please attend our quick check-in sessions to make sure your voice is heard
- Please fill in the tracking document - Critical for feedback

- The day you are on duty:
  - Keep an eye on the WA groups and respond if necessary
  - Verify the requests (use the template to make it quick)
  - After you have verified the new number and added them to the network - Please send the welcome video to them
  - If this is a newly diagnosed patient - get the PAXI point number from the person
  - Inform Rida with the Paxi point
  - Make sure Rida sends the care package














Get
Well
Soon


We are more than
Cystic Fibrosis

Finances

Heike Ludewig - Treasurer

Profit and Loss

April 2023 - March 2024

	Total	
	Apr 2023 - Mar 2024	Apr 2022 - Mar 2023
Income		
CF Fun Walk/Run	0	43461
CF Genes Day	13333	28211
Cycling 4 CF	10948	45716
Donations	65140	238642
Everesting	0	119825
Golf Day	51740	21350
Interest received	38855	15073
MySchool	19678	18673
Virtual 6.5km	3739	0
Total Income	**203434**	**544318**
Gross Profit	**203434**	**544318**

Profit and Loss

April 2023 - March 2024

	Total		
	Apr2023-Mar2024	Apr2022-Mar2023	
Income			
CF Fun Walk/Run	0	43461	
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Everesting	0	119825	
Golf Day	51740	21350	
Interest received	38855	15073	
MySchool	19678	18673	
Virtual 6.5km	3739	0	
Total Income	20343	54431	
Gross Profit	4	8	
Expenses	20343	54431	
Bank Service Charges	4 1365	8 1530	
Communication	0	3636	
Congress sponsorships	2897	0	
Courier	230	0	
Dues and Subscriptions			
Quickbooks			
RareDiseases	3140	0	
Zoom	1500	0	
TotalDuesandSubscriptions	4186	0	
GiftsandDonations	8825	0	
NewFrontiersExpenseFund	0	500	
PatientSupport	294241	0	Legal costs Vertex
PrintingandReproduction	8340	10700	
Salaries&Wages	395	0	
TShirts	52352	44488	
TotalExpenses	0	13369	
Other Expenses	368645	60854	
OtherExpenses			
TotalOtherExpenses	0	8636	
NetEarnings	0	8636	
	-165211	474828	

Notes: Legal Costs for Vertex case were funded from these fund-raisers:
~ Everesting ~ Golf Days ~ Cycling4CF ~ CF Fun Walk

Finances

Heike Ludewig - Treasurer

Balance Sheet

As of March 31, 2024

	Total	
	As of Mar 31, 2024	**As of Mar 31, 2023**
Assets		
Current Assets		
Accounts receivable		
Accounts Receivable	3070	0
Total Accounts receivable	**3070**	**0**
FNB Current Account	13351	16839
FNB Money Market Account	454756	625901
Nedbank Current Account	98480	0
Nedbank Investment Account	1091149	0
Petty Cash	6195	2850
Prepaid Costs	10000	0
Total Current Assets	**1677001**	**645591**

Balance Sheet

As of March 31, 2024

	Total	
	AsofMar31,2024	AsofMar31,2023
Assets		
Current Assets		
Accounts receivable		
Accounts Receivable	3070	0
Total Accounts receivable	3070	0
FNB Current Account	13351	16839
FNB Money Market Account	454756	625901
Nedbank Current Account	98480	0
Nedbank Investment Account	1091149	0
Petty Cash	6195	2850
Prepaid Costs	10000	0
Total Current Assets	1677001	645591
Liabilities and shareholder's equity		
Current liabilities:		
Accounts payable		
Accounts Payable	4271	0
Total Accounts payable	4271	0
Accruals	2720	0
Total current liabilities	6991	0
Shareholders' equity:		
Net Income		
Opening Bal Equity	-165209	448090
Registry Fund	130342	130342
SACFA Reserve	668622	0
Retained Earnings	521006	0
Total shareholders' equity	515249	67159
Total liabilities and equity	167001	64559
	0	1
	167700	64559
Notes:	1	1
Due to the merger of Central Region and SACFA, theNedbankaccounts(SACFA)havebeen incorporated into the balance sheet.	An appropriate portion of these funds has been allocatedtotheRegistryandSACFAReserveFunds	

Treatment for State patients

Dr Marco Zampoli - CF specialist



- Associate Prof Paediatric Pulmonology
  (Red Cross Children's Hospital (UCT)
- National Co-ordinator
  CF Registry
- Chair of MSAC,
  CFNFC

Access to Modulator Meds

- Access to Modulator Medication (Trikafta) for private patients achieved this year
- How? Advocacy, lobbying (Court Case, Media Attention, PRESSURE)









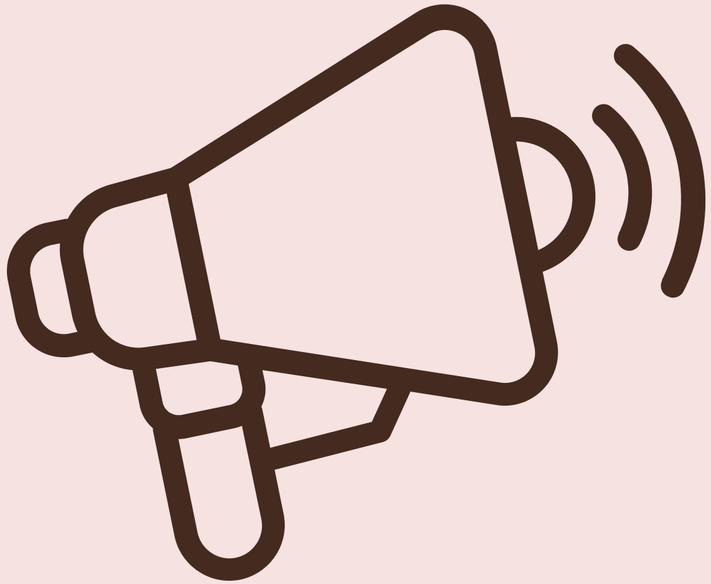
South Africa Association

Next Steps for State Patients

- Current status in Public Health Sector

- **How do we approach this?**

1. One hospital facility at a time
2. Push to get Trikafta on the National Essential Medicines List
3. Place pressure on Public Health Sector



Next Steps for State Patients



Support campaigns to help drive:

1. **Awareness** of the medication and its life-changing impact
2. **Pressure** to engage with Vertex ito pricing
3. Create a sense of **urgency**

Calling all state patients to sign up/volunteer to be involved - become a pioneer in the new frontiers of access to life-saving meds.

SCAN ME

Add your voice!

CF South Africa Association

Statistics

The number of patients that utilize state care! *

2/3



*Results from 2022 registry

Empowering the Patient

Rida Viljoen - Patient Empowerment



Patient Empowerment

Rida Viljoen - Patient Empowerment and Advocacy

There is no beauty, but the beauty of action.

- New position
- Detective: Go where it leads
- Global and national
- Roundtable collaboration
- Department of Social Development



Patient Empowerment

Rida Viljoen - Patient Empowerment and Advocacy

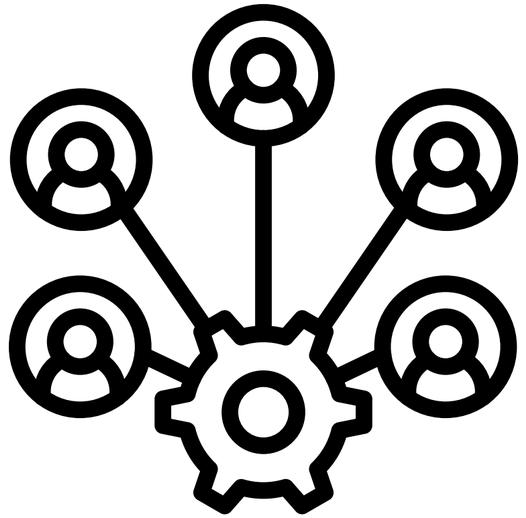
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Patient Empowerment

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NHI/
trikafta

Clinic Guardian

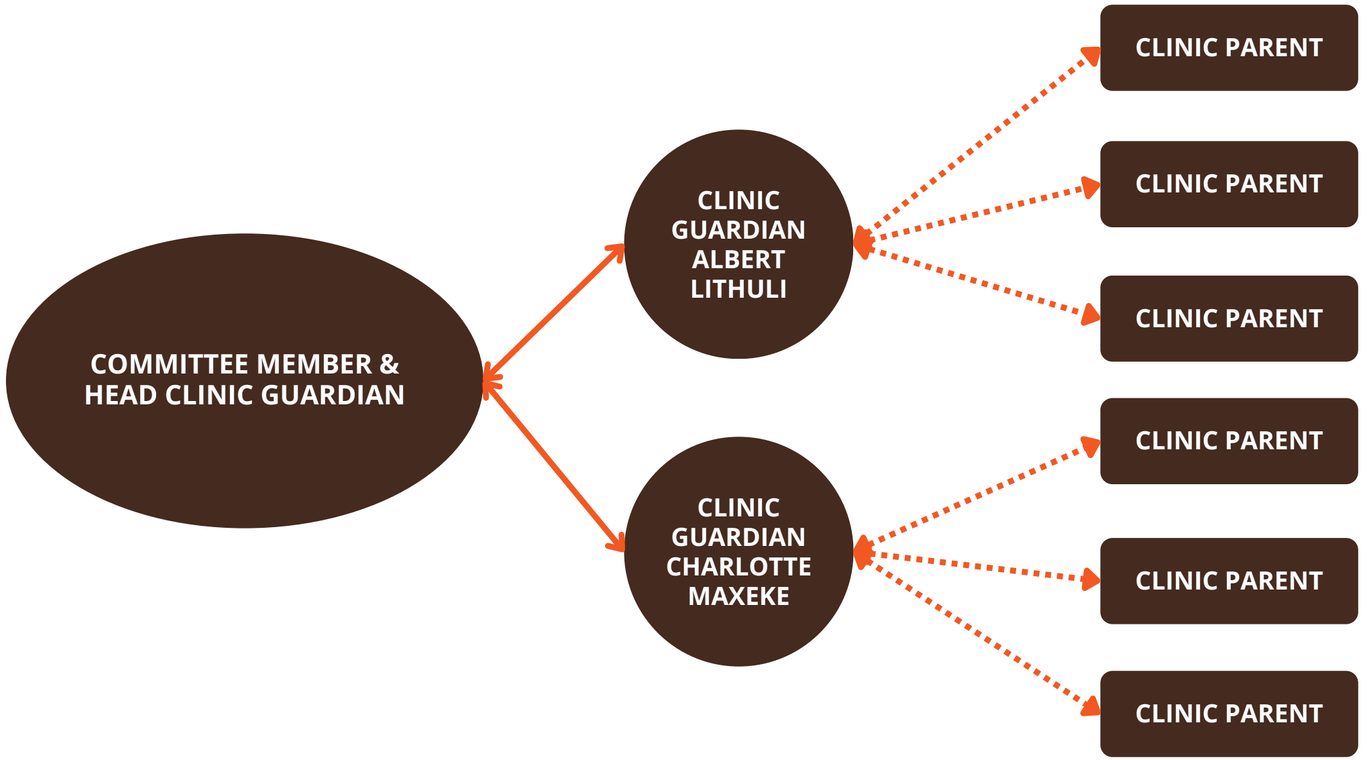
Annemarie Holtzhausen - Clinic Guardian



Clinic Guardian

Annemarie Holtzhausen - Clinic Guardian

- Introduction to the ‘Why’
- The problems we face alone
- The solution to our problems
- Please stand up to be a Clinic Guardian
- Clinic Parents and Adult Warriors, please join our Clinic WhatsApp Groups






SPRINGBOKS















Clinic Guardian

- The clinic guardian has to visit the clinic as this person already is the patient self or the caregiver attending the clinic
- Create a feedback channel / platform for all clinic warriors to get the opportunity to give feedback.
- QUARTERLY: Orchestrate focus groups for this purpose with the parents of their own clinic.
- Use information to develop strategies for the applicable clinic.
- Must be available to attend quarterly meetings as part of national strategy for state care in South Africa.
- Communicate this to the Committee Member so they can report it
- They must be able to phone / communicate with new state patients to comfort them and integrate them into the system - SACFA provides training according to guidelines.
- Make sure that the care package is posted / delivered to the new state patients - AND FOLLOW UP
- If they hear about a new diagnosis in the private sector, communicate it to the committee member so they can report it and put it in to action with Rida (The Patient Empowerment Manager)

Clinic Guardian

- Ensure that the clinic requests are communicated and followed up.
- Requests from parents
- Ensure that all new patients are welcomed and integrated into the empowerment system of SACFA
- Ask the doctors if there was any new diagnosis and ask for their details with the parents permission
- The Clinic Parent must endeavor to get ALL WARRIORS AND PARENTS to attend the clinic WhatsApp group
- Information on the clinic WA groups are for clinic information like clinic updates and requests.
- Make sure the doctors have the latest request form so they can communicate wants, needs and newly diagnosed with the Clinic Parent
- Communicate with the Clinic Nurse to help them with extra necessary clinic communication.

World Patient Alliance

Rida Viljoen - Patient Empowerment

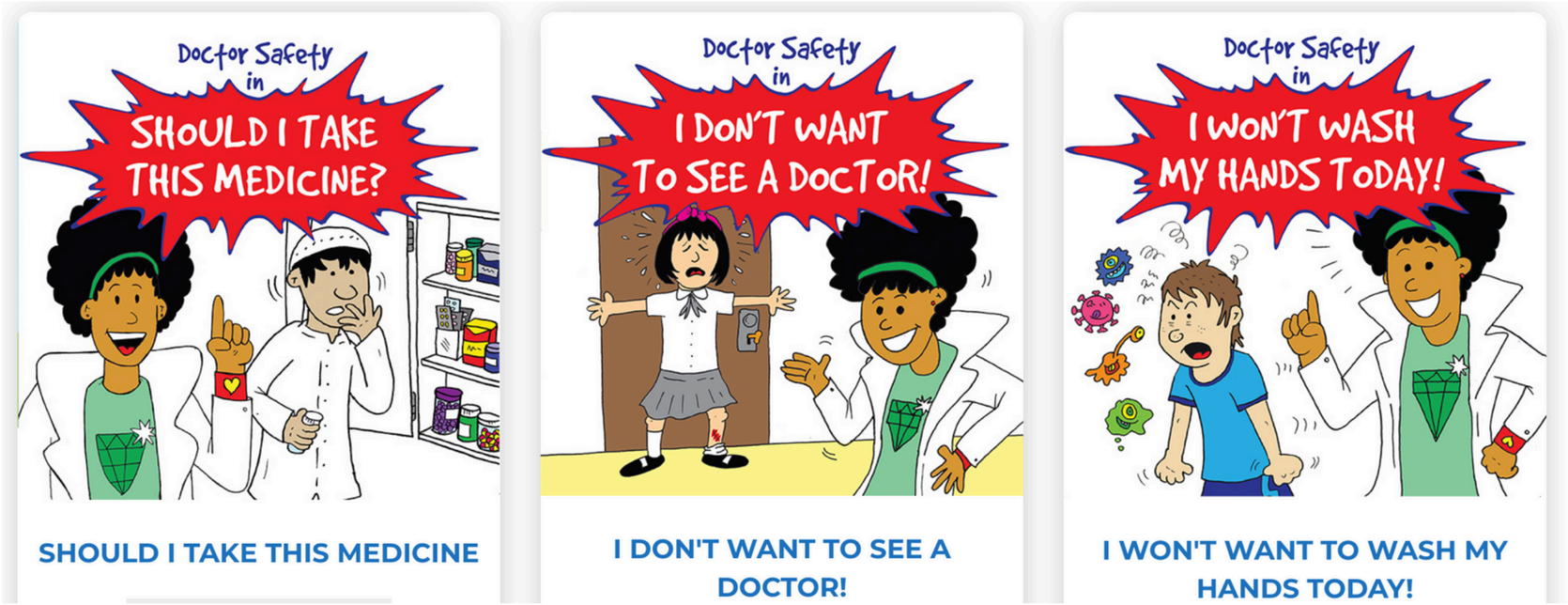
World Patients Alliance

Books

- World Patients Alliance Conference in Cape Town
- Patient safety league books - addressing critical themes like washing hands, going to the doctor and sharing medication.
- Kevin, Tara and David volunteered to Narrate the books on behalf of SACFA.
- If anybody is willing to help us translate the books into African languages, please let me know .

World Patient Alliance

Rida Viljoen - Patient Empowerment





WPA - Conference
Cape Town



IPASA business and Ethics Day - Joburg

Join Our Team

At the South African Cystic Fibrosis Association, our dedicated team is committed to providing support, raising awareness, and advocating for the needs of the CF community. Through a blend of fundraising, patient advocacy, and a strong online presence, we work together to make a meaningful difference in the lives of those affected by Cystic Fibrosis across South Africa.



Elections of Management Committee



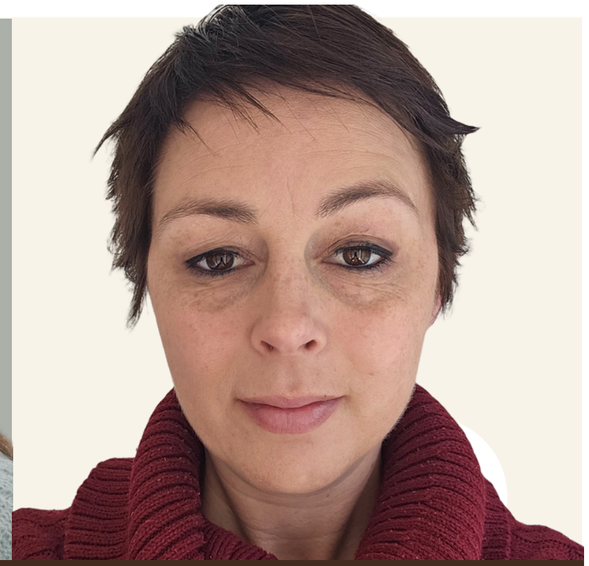
Rida Viljoen
Patient Empowerment Manager



Kimberley Keyzer
Chairperson



Heike Ludewig
Treasurer



Jolene du Plessis
Social media and Brand Manager

Elections of Management Committee



Alan Dunn
Fundraising



Annemarie Holtzhausen
Clinic Parent

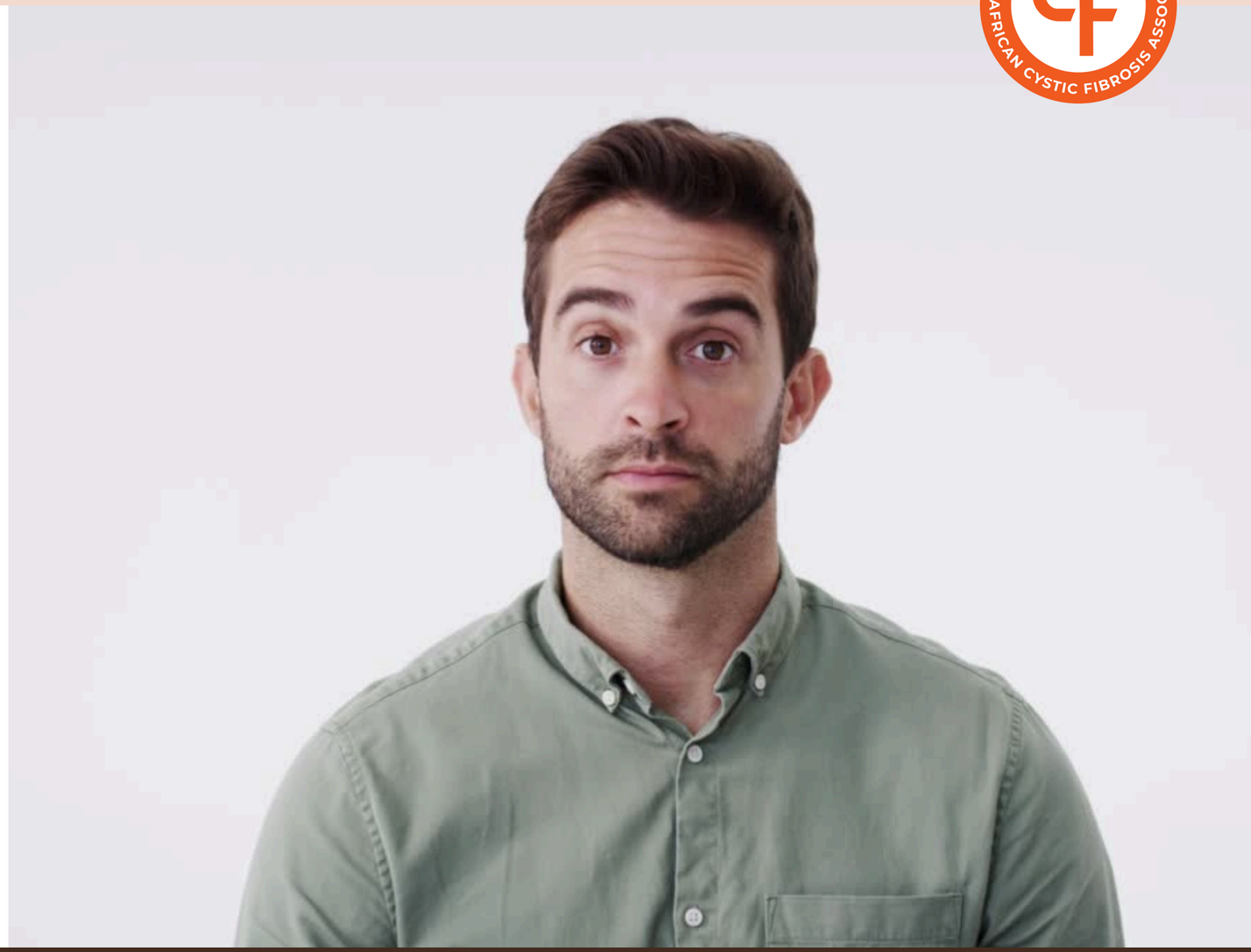


Your Name Here
Part of the committee

Role open

Secretary

- Set up committee meetings, Zoom events
- Write up and send meeting agenda
- Write up and send previous meeting minutes
- Handle committee members details





Questions & Comments



Thank you!

Thank you for taking the time out of your evening to join this event.

Email info@sacfa.org.za