



Minutes

Cornea donation in sub-Saharan Africa

Round Table Discussion

Our Vision

To contribute to the elimination of avoidable corneal blindness in Africa.

To supply patients with safe and high-quality tissue transplants.

With the help of patient care that is self-sustaining from within the country.

Our Aim

The aim is to **share knowledge and experience** in setting up donation programs and tissue banks by organizations worldwide,
to **bring together local and international experts**,
to seek options in **bundling synergies** and
to **raise awareness** of society, politics, and other multipliers on the topic of tissue donation.

Background

- Imports are currently necessary, but not enough in the long term
- Corneal transplants mostly come from countries such as the USA, and occasionally also from Germany
- Corona pandemic has shown limitations of importing tissue and increase of transport costs
- DGFG supports surgeons with corneal transplants during voluntary aid missions in Africa
 - Just a drop in the ocean
 - Costs that cannot be invested on a regular basis (20 corneas = 40.000€)
- Self-sustaining donation activities and local eye banking facilities are the only long-term, viable solutions!
 - Will build knowledge and expertise within the country
 - Will create jobs and infrastructure
 - Will reduce dependence on imports
 - Will keep reimbursement costs at a reasonable level as the cost of tissue grafts will be based on locally incurred recovery/retrieval costs rather than the cost structure in another country

With the Round Table we aspire ...

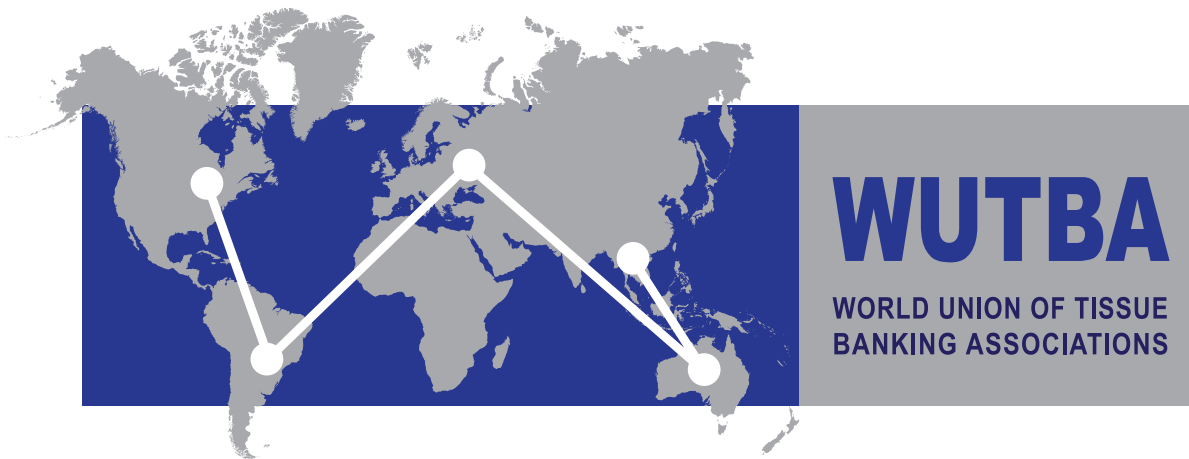
..to launch the idea to establish a **platform** that brings together the *novice and the expert* from all over the world:

..to create an **open space** that allows transparent **knowledge transfer** and **reliable networking** following the philosophy of WUTBA and GAEBA.

Co-operation instead of Competition



Networking is key!



- Thinking about all tissue types from the beginning.
- A cornea donation program can be a starting point for the donation and collection of heart valves, vessels, bones, amniotic membranes...

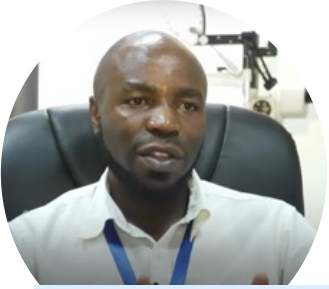


What you can expect from us

- **Consulting** regarding the establishment of donation and technically relevant infrastructures for the preparation and distribution of tissue with the involvement and training of your staff
- Support **exchange of know-how** with experienced individuals and organizations in this field by providing a network of relevant contacts
- Support in **educational work**, (regulatory) communication and advocacy
- Support in the search for **sponsors** for financial support
- Support in the **application** for funding through tenders

Presentation of the panelists





c.mwangala@lionsloresho.org

Christopher Mwangala

Corneal Retrieval Specialist / Eye Bank Coordinator / Eye Bank Technician at Lions SightFirst Eye Hospital
Loresho – Nairobi (Kenya)

sponsored by



- Realised 35 cornea donations (70 corneas) during Corona pandemic between 2020-2021
- Within the last 12 months, due to Covid and age related utility, he could only realise 5 donations
- Opt-in system, short time for talking to the family: call within 6 hours after death
- cold storage
- import of corneas from Eversight and SightLife (US)





fkorir@gmail.com

MD Fredrick Kipkoech Korir

Chairman Ophthalmological Society of Kenya,
Consultant Ophthalmologist at Lighthouse for Christ Eye Centre
Mombasa (Kenya)

- trained ophthalmologist and corneal surgeon
- main challenge: to get access to corneal tissue
- depends on import of tissue
- trains other ophthalmologist in corneal transplantation techniques



ruhagazep@gmail.com

MD Patrick Ruhagaze

Senior Consultant Ophthalmologist and Eye Surgeon,
Kisii Eye Hospital
Kisii (Kenya)

- has been working in Kenya for 7 years
- works in a remote area, 300 km away from the Capital in a social enterprise eye hospital and innovation eye centre „Kisii Eye Hospital“
- general ophthalmologist, not a cornea specialist
- does corneal surgeries for around 4 years now and is highly interested in cornea
- imports cornea from Eversight
- import is a challenge: patients have to wait for min. 3 months





mukiri66@gmail.com

MD Mukiri Mukuria

Consultant Ophthalmologist and Lecturer, Department of Ophthalmology / Manager of the Eye Center,
University Nairobi
Nairobi (Kenya)

- corneal specialist, trained at Aravind in India
- likes to continue with his training in corneal transplantation techniques
- wants to apply his knowledge → needs access to tissue





eyebank2015@gmail.com / negademessie@yahoo.com

Nega Demessie

Awareness Coordinator
Eye Bank of Ethiopia
Addis Abeba (Ehtiopia)

- approx. 500 cornea donations per year
- part of donor notifications recieved is via voluntary phone calls
- Eye Bank of Ethiopia founded by Orbis International and Government
- SightLife supports Eye Bank of Ethiopia with training and expertise
- distribution of corneal transplants to 10-12 transplant centres in Ethiopia
- wishes an eye bank association for Africa





angelameric9@gmail.com

Angela Meric Birungi

Ophthalmology postgraduate student,
Mbarara University of Science and Technology
Mbarara (Uganda)

- national law on organ and tissue donation in Uganda just have been passed
- wants to establish an eye bank in Uganda
- part of an initiative that wants to increase the number of tissue donations
→ run a survey in COECSA regions to collect data about the needs, barriers, etc.
- with information and awareness campaigns they want to reduce cultural barriers



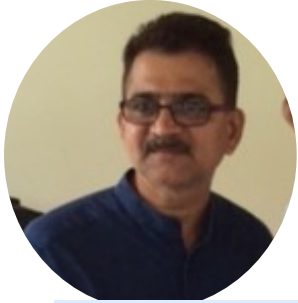
arungasimon@gmail.com

MD Simon Arunga

Ophthalmologist,
Mbarara University of Science and Technology
Mbarara (Uganda)

- likes to set up Uganda's first eye bank
- imports (e.g. from Sri Lanka) are expensive and involve risks (such as strike of pilots, logistics...)
- a lot of good will from donor and political aspect is already there
- need of support and guidance from experts in this field
- already exchange with experts within Africa (COECSA)





vngokhaleeye@gmail.com

MD Vishwanatha Gokhale

Consultant Ophthalmologist

Lions Medical Centre – Lions Eye Hospital

Mombasa (Kenya)

sponsored by



- has been working as corneal specialist in Mombasa for 14 years
- already realises cornea donations: small (especially) Indian community who donates cornea
- gets donor notifications by phone call, from e.g. Lions members, physicians, relatives
- between 7-10 years he collected around 70 corneas + 30 imports → he performed around 100 transplants
- convinced that awareness work is very important: „**You have to show people the results.**“
- cooperates with Cornea Help – a German organisation that organises and finances corneal transplantations





sandrav@satiba.org.za

Sandra Venter

SATiBA President. Donor recovery and awareness manager

Bone SA

Cape Town (South Africa)



- grateful for the Round Table and the interest in tissue donation.
- In South Africa, the situation is almost reversed: there used to be a high number of cornea donations in South Africa, but today there are **only 3 free-standing eye banks**.
- In South Africa, the number of cornea donations has dropped from 1,200 per year to only 50 per year, nationwide.





heather.machin@unimelb.edu.au

PhD Heather Machin

Chair of Global Alliance of Eye Bank Associations (GAEBA),
Senior Project Manager, Lions Fellow, Lions Eye Donation Service, CERA– University of Melbourne
Victoria (Australia)

- GAEBA helps and supports networking and brings together the experts on the topic of cornea donation and eye banking
- „I am going home to my country tomorrow and look after my country. This is your continent, and it is your responsibility to step up and to decide what you want, what you want from us and not the other way around.”
- GAEBA can help create a platform, build an interest group or an association





Patrick.Emery@sightlife.org

Patrick Emery

Vice President, Asia & Africa
SightLife (US)
Delhi (India)

- experience in donor operations for the largest eye bank in the world, based in the USA
- works internationally and on best practices for Asia, Africa and Latin America
- worked together with Eye Bank of Ethiopia and Eye Bank/Hospital at Dr. Shroff's Charity Eye Hospital (Delhi, India) together with Dr. Manisha Acharya
- **„There is an immense need and this is a very, very important event.“**





macharya@sceh.net

MD Manisha Acharya

Ophthalmologist and Medical director of the Cornea Bank,
Dr. Shroff's Charity Eye Hospital (SCEH)
Delhi (India)

- experience in setting up donation programmes and in training of eye donation counselors
- **SCEH has its own academy for training eye donation counseling** → open for external experts
- works together with DGFG (Dr. Anna Salz) in a joint project, funded bei GLZ, to improve cornea donation in Northern India





martin.boergel@gewebenetzwerk.de

moderator of the discussion

Martin Börgel

Managing Director

German Society for Tissue Transplantation (DGFG)
Hannover (Germany)

- over 20 years of experience in tissue donation
- managing director of DGFG (and former DSO-G) since 2002
- general secretary of WUTBA
- member of the German Lions Club Wedemark, EEBA, EATCB



anna.salz@gewebenetzwerk.de

country presentation

PhD Anna-Katharina Salz

R & D – International Project Management

German Society for Tissue Transplantation (DGFG)
Hannover (Germany)

- prepared and organised this round table together with Sandra Venter and Kristin Kleinhoff
- member of EEBA



Further panelists

Persons who wanted to participate but could not due to visa and travel problems are marked in blue

Country	City	Last name	First name	Institution	Role
Germany	Hannover	Kleinhoff	Kristin	German Society for Tissue Transplantation (DGFG)	Organiser of this round table
Germany	Hannover	Rausch	Anna	German Society for Tissue Transplantation (DGFG)	Tissue coordinator
Germany	Hannover	Kniese	Jan	German Society for Tissue Transplantation (DGFG)	Physician and expert for tissue donation
Kenya	Nairobi	Chege	Evelynn	Kenya Tissue and Transplant Authority	Head of Technical Services
Nigeria	Ibadan	Ogundipe	Ayobade	University College Hospital Ibadan	Consultant Ophthalmologist
Rwanda	Kigali	Mathenge	Ciku	Rwanda International Institute of Ophthalmology, RIIO	Consultant Ophthalmologist
South Africa	Capetown	Mogari	Moji	Bone South Africa	Medical Director
South Africa	Durban	Tonnesen	Carol	KZN Cornea & Eye Association	Manager
South Africa	Pretoria	Horn	Marna	Centre for Tissue Engineering	Coordinator
South Africa	Pretoria	Elize	Scheepers	Centre for Tissue Engineering	Coordinator
South Africa	Port Elizabeth	Theunis	Botha	Bay Tissue Institute	Ophthalmologist
USA	Madison	Troha	Stacey	Lions Clubs International – Eye Bank Working Group, LCIEBWG	Lions Eye Bank Wisconsin
USA		Hajira	Mahdi	Lions Clubs International	Department Manager, Program Development, Service Activities
USA		Brosius	Jason	Lions Clubs International	Chair

Go to www.menti.com and use the code 6828 4023

What are your expectations of the Round Table?
What topics do you want to discuss?

corneas into south africa
donation methodology
develop a working model
improvement of skills
getting government help
equity
establish a plan
training
offer support
access to all
knowledge
independence
bank
education
understanding
networking
sustainability
learning
knowledge
collaboration
exchange
funding
opportunities
international grants
interaction
functioning
inspiration
equipment
partnership
partnerships
learn more
responsibility
fairness
notification system
share resources
network
resources
establish
working
cornea donation
investors
awareness
understand needs
sustainable awareness
regulations and guideline
system development
who is doing what to help
gain commitments
road map to eye banking
networking for cornea
collaboration s
price
donation
technology
interest
gaining
advice
sop help
research
feasibility
together
communication
cold storage
amniotic membrane
for eye bank setup
affordability
sharing knowledge

Mentimeter



33

An example: cornea donation in Mombasa

Dr. Vishwanatha Gokhale about his experiences

- Support from Cornea Help → a German non profit organisation, that collects funding for corneal transplants (imports from US and Germany)
- follow-up of the patients also has to be organised and financed!
- No enucleation, **only retrieval of the cornea** → puts it into the refrigerator and preservation medium (cold storage, no eye bank), deswelling at night
- parallel: organisation of the transplantation, has waiting list of patients
- retrieval within 6 to 8 hours after death
- hospital is run by a local Lions Club with around 50 members, who call Dr. Gokhale (voluntary donor notification)
- also donor notifications by doctors who treated the deceased patients
- Lions Club members important role as multipliers for the community
- almost every notification comes from Asian (Indian, Hindu) community
- only 3 or 4 donations from Christians, none from Muslims
- no donor registry, but a document to register as potential donor at the hospital



Could organ culture improve the donation?

Pro

- more time for the family to think about tissue donation

Contra

- organ culture can increase or improve the allocation site but not really the donation side
- If somebody is willing to donate, you can arrange that in such a short period of time.
- “With every hour that you wait for consent the logistical loss rate goes up dramatically: As far as the cell integrity and quality of the cornea is past 24 hours, I don’t think reducing the urgency is helping. Urgency is important for this topic. I don’t think that just extending preservation time is going to improve outcomes.” Patrick Emery
- not a question of time but of awareness and knowledge → educational work must start earlier, during lifetime

What are the main barriers for tissue donation?

Cultural and religious aspects

- **death** is a very **sensitive issue** for the family – much grief
- body needs to be **buried whole**
- **religious leaders (e.g. priests)** play very important role for the African communities
- challenge with religious leaders: fear that the number of people coming to church could decrease
- in general, people will accept tissue donation easier when religious leaders are in favor for it

What are the main barriers for tissue donation?

Lack of knowledge – high need for awareness campaigns

- dissertation about knowledge and willingness to donate organs and tissues shows that 30 percent of the population wants to donate → **high potential**
- **awareness program** with the community where you ask people to pledge “**when you die you can save sight**” helps, then they can register voluntarily
- „Every time we do a transplant, we put it in the newspaper.“
- **Even in the ophthalmology community not enough awareness**, doctors talk barely about donation → awareness is the main thing we lack
- Manisha (India): „Because of **many awareness campaigns** we can steadily overcome barriers.“

What are the main barriers for tissue donation?

Lack of knowledge – high need for awareness campaigns

- Same problem with blood transfusion: with advocacy and awareness you can be successfull → **make aware of the need and the benefits of tissue donation**
- similar situation at the beginning of HIV / AIDS pandemic: everyone was scared, thought it was witchcraft → what helped us was a lot of **lobby work with religious as well as political leaders**
- bad time to approach the family with the topic of tissue donation so shortly after the death of a family member
→ better to **start earlier**, for example with **awareness work and education at school**

Challenges in the donation process

Challenge in getting death notifications and logistics

- most deaths occur at home and outside the hospital → **but small number of deaths at hospital would be a good start for a donation programme**
- sick people go to nearest pharmacy and stay (or even die) at home
- hospitals are understaffed: challenge in getting timely notifications
- body gets quite fast to the morgues
- challenges in electricity and cold storage
- even before pathologies come in to get cause of death, deceased gets formaldehyde
- In governmental hospitals there are counselors in hospitals for general conditions → they could be utilized for talking to the patients about tissue donation



How do you get donor notifications?

- voluntary phone calls (from Lions Club members, doctors, families)
 - notification from grief counselors
- no system to receive death notifications on a regular basis



No donor notifications – no tissue donation

“In the US, there is a law that every death that occurs in a hospital must be reported to a donation program within one hour. If not, the hospital could lose national funding. ... But, as Doctor Manisha knows, we have been working on mandatory death notification in India for over a decade. We still don’t have that. We still though have incredibly good donation volumes based on relationship and **incentives**.” Patrick Emery, US

„Within the health system there is a reporting system for death notifications. Deaths have to be notified in a certain period of time. Death notifications have to occur whether it is a private or public hospital because it is required by the ministry of health. It is mandatory. Good political will would help us getting these notifications.” Angela Meric Birungi, Uganda

You need someone to push things forward.

“If you want to develop a strong donation program, you need to have high level support – whether that’s from a government hospital CEO, someone from the ministry of health, someone who motivates the employees at the lower levels to make timely death notifications. To support donation, get the police commissioners to support donation. Someone needs to be going to push things forward.

If you are working at the management level of the government or hospital or even of the police department, there is so much risk and so much concern within donation, that people don’t make this decision or don’t make these types of decisions, because they are always afraid of what their senior is going about that to do.

People at the top, at the ministry of health level, the head of the police forces, they are willing to support with education. We send them to other countries to learn and to see those donation programs in real in first-hand. **But you have to start at the top.”**



Proactive counseling as key for success

- For organ donation, India has a central help line for every region in the country
- But for tissue donation, only 30 eye banks work for 80 percent of all the donations → donation still not established in every region.
- “15 years ago, we had the same situation in India that you have today in Africa.”
- We started the hospital cornea retrieval program with proactive counseling by the employees of the eye banks.
- the next of kin has to consent: When we depended on voluntary phone calls the numbers were low.
- **pledge cards and pro-active contact via the eye donation counselors helped!**



What you can do to get donor notifications:

Mandatory death notification policy at national level will increase donor volumes.
Challenge: changing national policy takes many years and is very difficult to achieve.

In the meantime...

- **start thinking about getting the mandatory death notification:** establish relationships at the trauma center, mortuary, medical examiners office etc.
- **involve the hospital management and treating doctors** – awareness work starts at the hospital because even the medical staff lack sufficient knowledge
- **create a mechanism where you receive timely notification one or two hours after death:** maybe with someone who is working on that 8 or 10 hours a day, calling hospital staff on a regular basis.
- **Be as independent of other people as possible** in getting your information.
- **Be proactive**, do not wait for phone calls or registrations.
- **influence the people right at the top at political level**

The sooner you start with the 10 years, the sooner you will get to the 10 years.



Start thinking about an economical level.

Public relations work and awareness campaigns are important success factors but only work in the long run.

In the meantime...

- **analyse and understand your area:** Check how many people die in one hospital and how many hospital one coordinator could reach.
 - **allocate resources** and place a coordinator in a surrounding where you have the potential to really use his workforce.
 - **pay the hospital an incentive for getting continuously death notifications and information** you can analyse for medical screening, for getting you a blood sample (for running tests) or for giving you a room for the retrieval.
 - **But: Do not pay for donations!** Just pay for extra work.
- **Establish a donation programme in the non-profit sector.**

Tissue donation is attractive for hospitals.

- Hospitals could **benefit from an eye bank that is able to cover more than the own transplants and the own patient care.**
- **Thinking in network structures:** Hospitals can benefit from allocating excess tissue to other hospitals.
- **Eye Donation Counselor is much cheaper** than having a doctor for this job of counseling and screening.

Internalize the principle:

Always medical, not financial indication for transplantation.



Start thinking about an economical level

“In the India context you need around 400 transplants per year to be economical break even. If you are partnering with the government, they may allocate fewer numbers and give you free space – 100 or 200 transplants could be sufficient. **The reality is you have to start somewhere.** If you are looking for types of financing, you need to be ok with few donations in the first month or the first year. **But when it starts going, you will increase the numbers.**”



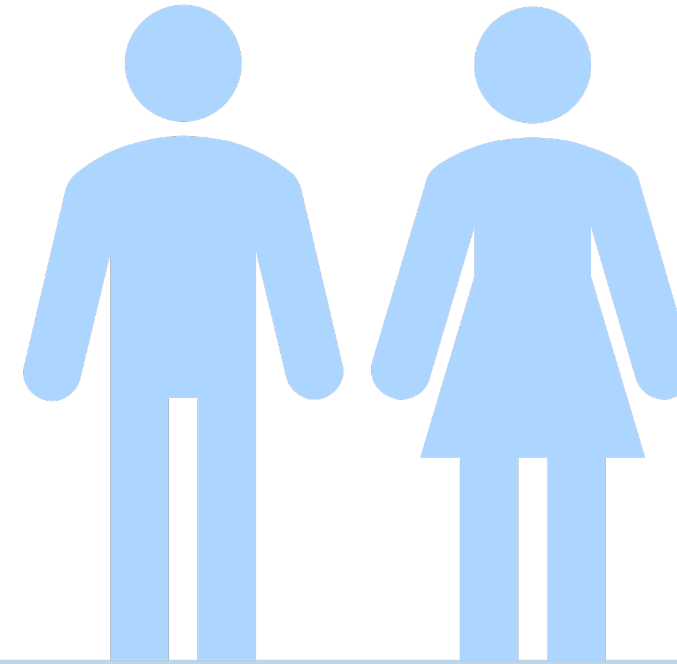
It is more than eye donation counseling.

- always **ask the relatives for donation after the patient's death**
- eye donation counselors have **good relationships with the relatives, families, doctors and nurses**
- **eye donation counselors help the families** with getting death certificates and helps them organize the funeral

Eye Donation Counselor: What is the perfect person?

Pick the right person

- Empathy and desire to help, communicative
- Background not very important, but helpful if the person is a nurse, biologist, paramedic, preparation assistant
- Usually nurses and doctors are not trained for such next of kin interviews together with all the important information about tissue donation, and they lack time
- Treating doctors are not ideal person to talk about donation → people could assume they see patients as potential donors
- Better: train your own donation counselors and build strong relationships with the hospitals and the hospital staff



Create a plan of actions

- **analyse your area** for hospitals/mortuaries and potential hospital death
- **cooperation and awareness work with clinics:**
 - Inform clinical doctors about tissue donation
 - ask surgeons who need tissue transplants to be proactive
 - win hospital staff as multipliers
 - Convince hospital manager from economic profile
 - Check if any hospital structure can be utilised/linked to to receive death notifications
- **building a team of counselors and recovery specialists**
- **training and practice** (in other countries or other eye banks), e.g., SCEH training academy is open to outside countries, Eye Bank of Ethiopia
- **Networking:** go to your local Lions Club, join WUTBA or GAEBA, connect via Sightlife
- **learn from existing structures**, e.g. for blood donation
- **start awareness & communication activities** in your communities

Create a plan of actions cont.

Long-term:

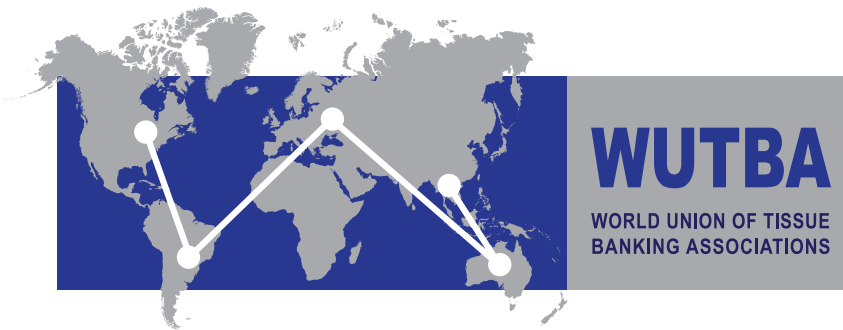
- Legal Policies
- Look for Funding and cooperation opportunities
- Awareness & Communication activities in your communities
- Implement hospital corneal retrieval programs (HRCP)

What else can I do?

1. **Do not compete, use each other (1 person can donate cornea, heart valves, vessels, bones etc.)**
2. **Stay connected and up to date** – regular updates on changes in your own country (regarding legal policy) / clinic / eye (tissue) bank, etc.
3. **Personal follow-up meeting every 2 or 3 years** – maybe at other upcoming conferences (e.g. COECSA, SATiBA ...)
4. Ownership of follow-up activities – **who champions which activities?**
5. **Build a special interest group** and find a person
 1. who coordinates the group and organises meetings and chats
 2. for researching on the topic of funding programs
 3. for researching on the topic of training programmes and useful fellowships

Networking is key!

Time for a special interest group?



Training

Training for Eye Donation Counseling

Dr. Shroff's Charity Eye Hospital (SCEH), Delhi, India:

- Training at SCEH Eye Donation Counseling Academy (25.000 Indian Rupies / 300 USD) for 14 days
- Costs in total around 2.000 USD (incl. hotel, flight etc.)

Others:

Tissue Banking & Advanced Therapies Training Program

<https://tpm-dti.com/training/tissue-banking-and-advanced-therapies-training-program/>

Online Course: 11th April – 11th June 2023, 10 Credits

Eversight: Webinars

<https://www.eversightvision.org/webinars/>

Eversight's global initiatives to combat corneal blindness



Funding

GIZ

funding program Hospital Partnerships

<https://www.hospitalpartnerships.org/hgp>



Funding German - African

The funding program Hospital Partnerships

The GIZ funding program Hospital Partnerships - Partners Strengthen Health promotes cooperation between German hospitals, universities, colleges, and non-governmental organizations and those in partner countries. Hospital partners are active worldwide in all medical fields. The program is implemented by the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH. It is commissioned and financed by the German Federal Ministry for Economic Cooperation and Development (BMZ) and co-financed by the Else Kröner-Fresenius Foundation (EKFS).

- <https://www.hospitalpartnerships.org/hgp>



'Global' line of funding

The "Global" funding line is aimed at German institutions (clinics, hospitals, associations, foundations, etc.) that have an institutionalized partnership with a medical institution in a low- or middle-income country. It is advertised twice a year. The partners carry out further education and joint training. The aim is to improve health services worldwide and provide people with optimal medical care.

- Maximum funding amount: €50,000 based on a signed subsidy agreement
- Funding period: 2 years
- Call for proposals: 2x/year - spring and fall of each year



HOSPITAL
PARTNERSHIPS



Contacts

roundtable@wutba.org

PhD Anna Salz anna.salz@gewebenetzwerk.de | +49 511 563 559 357

Kristin Kleinhoff kristin.kleinhoff@gewebenetzwerk.de | +49 511 563 559 34

German Society for Tissue Transplantation – Deutsche Gesellschaft für Gewebetransplantation (DGFG)

Feodor-Lynen-Str. 21 | 30625 Hannover/Germany





Lions Deutschland
Stiftung der Deutschen Lions

Geuder[®]
Precision made in Germany



GLOBAL ALLIANCE
OF EYE BANK ASSOCIATIONS



**Eye Bank Association of
Australia and New Zealand**



Lions Club Wedemark
We serve. Wir dienen.



KLmedical^{GmbH}
Ein Unternehmen der Raguse Verwaltung

DGFG
DEUTSCHE GESELLSCHAFT FÜR
GEWEBETRANSPLANTATION
GEMEINNÜTZIGE GESELLSCHAFT mbH

Thank you!

Sponsors of the Travel Grants