

**STOP
MARRYING
YOUR
NIECE!**

(or uncle, or cousin)

**one doctor's fight to overturn a social
custom and prevent deafness.**

***Dr. Najoo Varkey M.B.B.S. M.D.
(Pediatrics)***

STOP MARRYING YOUR NIECE!

(or uncle, or cousin)

Dr. Najoo Varkey

This book is about the work that I have been doing at the Sheila Kothavala Institute for the Deaf (SKID), Bangalore from 1989 till the present. It deals with the very tragic problem of consanguineous or blood marriages – (between uncle-niece and/or first cousins) – that are responsible for deafness and a host of other disabilities.

My hope is that the publication of this book will **create an awareness that “deafness due to consanguineous or blood marriages is 100% preventable”**(David P. Haxton), and that we can all join in the efforts to work towards preventing thousands of children from being born deaf or with other serious abnormalities.

From the time I started doing voluntary work at the Sheila Kothavala Institute for the Deaf (SKID), Bangalore I have been searching for an opportunity to let people know about the wonderful and genuine work done by the Principals, Mrs Margaret Joseph (former) and Mrs Jessy Samuel (current), Mrs Lalitha Xavier (in charge of administration) and all the teachers and staff members at this institute.

The total involvement of all of the above, who to this day spare no effort when it comes to the welfare of the children, academically or otherwise, needs special mention. Without their dedication and hard work, the school would not enjoy the reputation of being one of the finest schools for the hearing impaired in Karnataka.

I would also like to acknowledge the parents and children who form an integral part of the SKID community. The parents, who despite insurmountable odds, continue to bravely face their circumstances and seek out the best opportunities for their children's well-being. And the children, who's wonderfully resilient attitude and demeanour is truly admirable.

I wish the entire SKID family many, many more years of success and excellence!

A note from Dr. Varkey

A very special thank you to my 19-year old granddaughter, Ava Rego, who single handedly took on the task of designing and presenting this book, and did it with such brilliance. Thank you Avaloo, this wouldn't have been possible without your thoughtful and loving effort.

Dr. Varkey



A note from Ava

When I first started working on this book, I must admit that I had a narrative in my head, that the story I was compiling was one of *disappointment*. If only the incredible work of my grandmother (who I call Ammy) had actually done something, if only it had caused the government to ban consanguineous marriages, or become a national if not internationally acclaimed campaign, if only, if only, if only. I have since come to realise, **that narrative could not be further from the truth**, that this is actually a story of *hope* and *triumph* - for three very important reasons.

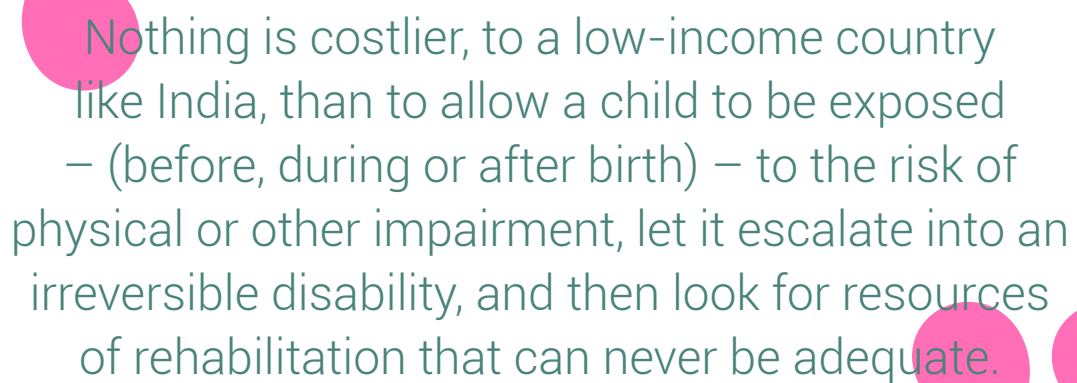
Firstly, social customs are some of the most valued and protected parts of any culture, and this makes them the hardest to challenge. Imagine if a doctor discovered that eating cake on your birthday was responsible for causing a deadly disease, and so they told you that from now on, you should stop eating cake. No matter how much of an expert they were, or even if the government made birthday cake illegal, would you be ready to give cake up forever? I realise that there is a *big* difference between consanguineous marriage and birthday cake, but what they have in common is that they are social customs - things that we will be reluctant to stop doing, because they are so deeply embedded in what we consider to be normal life. So, overturning a social custom is extremely difficult - even if you have knowledge, time, money or people on your side. Ammy had about *half* of these things: she had the **knowledge** that consanguinity increases the chances of deaf offspring; and she *made* the **time** to research, write about and then meet with people to share this knowledge. She didn't really have the **money** or the **people-power**, but she made do - enterprisingly using her social network to fundraise, and enlist people to help her along the way. Given that the odds were stacked against her in the social-change game, Ammy accomplished the unimaginable. She did it with a lot of help, but ultimately, she single-handedly led an initiative tackling culturally-induced deafness, right from the medical discovery of the problem all the way to the social campaign to raise awareness about it!

Secondly, Ammy's efforts have been tremendously effective, for the simple reason that they actually reached those South-Indian communities who practice the custom of consanguineous marriage, unaware of its consequences. Getting a government to legislate on a social issue, whilst incredible, doesn't guarantee that it will be implemented effectively (or at all) on the ground. Similarly, although it is fantastic if the world finds out about your social efforts, it doesn't mean that they will reach the communities who need to hear your message. By contrast, what Ammy did was create radio and TV spots, which were far more likely to reach her target audience than a government policy mandate (we all watch tv!). More importantly, she had them translated into multiple languages, which meant that *all* members of her target audience could truly understand her message. In essence, she spear-headed a strategic, bottom-up campaign that converted her message into an accessible medium and then delivered it directly to the people who needed to hear it most.

Thirdly, the story isn't over yet. This book is about capturing Ammy's efforts, so that future doctors and activists alike might have the resources to continue her legacy. Ammy has done the monster share of the work so far, so it's time to even the workload. I am certain that the issue of consanguinity and deafness will have its day both in government and in the international arena. It's up to us to take Ammy's work and bring it to both of these spaces, and I sincerely hope that this book and my absolute legend of a grandmother have inspired you to do so!

- Ava





Nothing is costlier, to a low-income country like India, than to allow a child to be exposed – (before, during or after birth) – to the risk of physical or other impairment, let it escalate into an irreversible disability, and then look for resources of rehabilitation that can never be adequate.

David P. Haxton
*UNICEF Regional Director for
South Central Asia*

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yellow pages provide additional information for eager readers!

Sheila Kothavala
Institute for the Deaf



It started in 1989.

A very close friend, a doctor, who had been doing voluntary work at the Sheila Kothavala Institute for the Deaf (SKID), wanted to retire due to ill health and asked me if I would volunteer in her place. She was very keen that I did so, but I wasn't! However, not to disappoint her I agreed to try this out for a while.

So, during September 1989, I made my first official visit to SKID. SKID is one of the oldest schools for the hearing impaired (HI) in Bangalore. The land was donated by the Kothavala family in 1967, in memory of their daughter Sheila, who was HI. It started in a very small way but over the years the student strength slowly grew to around 200. It is purely a 'day' school, starting from KG to class X.

Surprisingly, as a Pediatric Consultant doing private practice, I had never had a single HI patient and the few disabled patients I did have were either victims of polio or rickets. So, this was a completely different environment for me. These 200 odd children had no medical records, no parents accompanying them to give a history or carry out requests for investigating etc. The class teachers came with every class and did their best to help. But it was daunting! However, it also seemed like a situation crying out for attention and so I stayed on. It took almost a year to examine each child, meet the parents (who spoke various languages - teachers to the rescue again!), record a proper medical and family history and make a permanent medical record card for each child.

This could be done because of the total involvement of the principal, the school secretary and ALL the teachers - a highly dedicated group who, to this day, spare no effort when it comes to the wellbeing of the children, academically or otherwise.

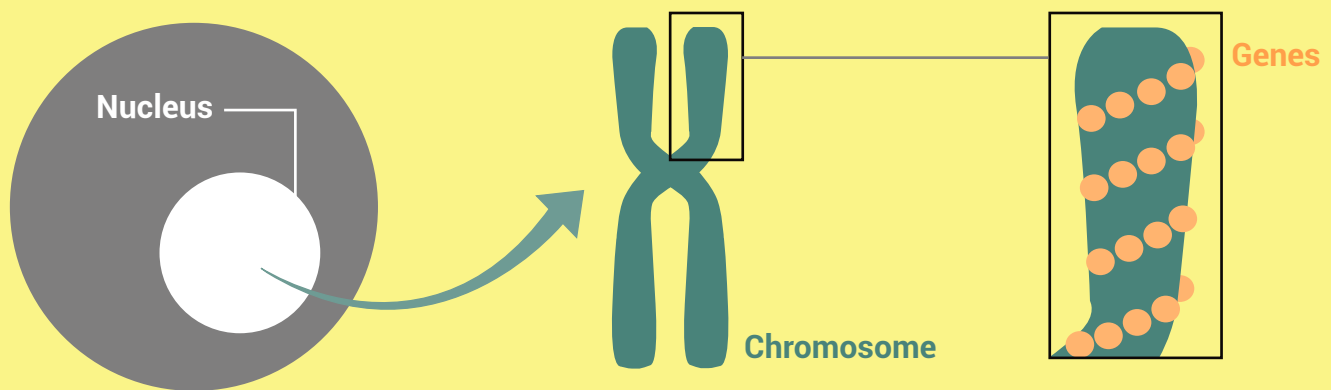
It was the recording of the family history that brought out the problem of consanguineous marriages being responsible for deafness in 50-55% of the children.

a crash course on genetics: why does consanguinity cause deafness?

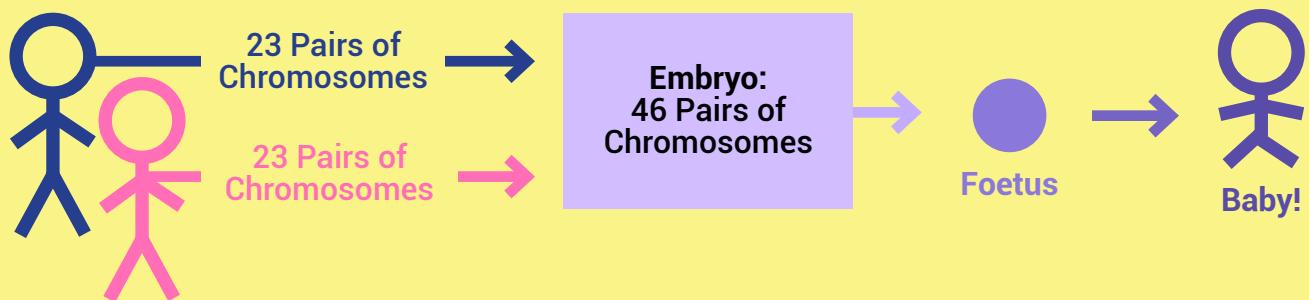


To understand how Consanguinity can cause various diseases one needs to have a brief knowledge of **genetics**.

Each cell in our body has many parts and each part has its own function. The most important part of the cell is the **nucleus**: the 'governor' for everything, so to say. Long strands of a special substance - the **chromosomes** - are stored in the nucleus. Attached to these strands (like a string of beads) are microscopic protein molecules called **genes**.



At the time of conception, when the 23 pairs of Chromosomes from the Ovum of the mother and the 23 pairs from the Sperm of the father come together, half the cells from the Ovum and half from the Sperm unite to form the 46 chromosome **embryo**. This grows in the uterus to become a **foetus** and eventually the precious **baby!**



Sometimes, however, a gene or chromosome becomes *abnormal* producing a specific disease. As the cells divide and then unite, as explained above, the abnormal genes or chromosomes will be carried from cell to cell, carrying the specific disease with them.

The custom of **first cousin marriages** and **uncle/niece marriages**, more common in Southern India, is what is referred to as **consanguineous marriages**.

In a large, extended family, made up of mother, father, sons, daughters, grandparents, aunts, uncles cousin etc. many members might suffer from a common disease eg. **Congenital Deafness (CD)**. If they keep marrying among themselves then it is obvious that the same defective gene will keep getting transferred from person to person and the disease will keep spreading through generations.

The gene responsible for "**Nonsyndromic Recessive Deafness**" or the **Deafness due to Consanguineous Marriages**, has now been discovered and is labeled **Connexin 26 on Chromosome 13**.

Nonsyndromic Recessive Deafness is just one disease caused by Consanguineous Marriages. In actual fact, there are thousands of different diseases mentioned in medical literature, due to consanguinity.

That is why a campaign to prevent consanguineous marriages is so necessary.



Scary Statistics: Consanguinity and Deafness in South India

52%

of children at SKID are deaf because of consanguineous marriages between their parents.

This figure has remained constant over the past 20 years.

50%

of marriages are consanguineous... even today in rural Tamil Nadu and Andhra Pradesh" - *G. Kumaramanickavel, a renowned Ophthalmologist from Chennai*

40%

of deaf children come from consanguineous marriages... at almost every school for the deaf in South India"

- *Dr Ishwar Chander Verma, a pioneer researcher at AIIMS*

consanguinity who?

Every year, as I checked the children and got their histories I became aware of a pattern emerging. If say 30 children were admitted then 16 or 17 would have a history of consanguineous marriage between their parents. As I myself had never heard of this condition I wondered, at first, whether this was all in my imagination. But when this continued over 4 – 5 years I felt I had to either prove it or disprove it. Because, if real, then something needed to be done.

This took me to the library at St. John's Medical College, Bangalore, where I went through several ENT (Ear, Nose & Throat) Journals. And, lo and behold there it was! Several large families had been recorded with hearing loss due to consanguinity, in many of the European journals! This, for me was proof that I wasn't imagining the whole problem.

But then, the next big question what should I do and how should it be done? It was a Blank Wall. It was the first time that the school staff, the members of the school committee and members of the Deaf Aid Society had become aware of this condition.

I kept talking to senior medical and administrative professionals, from well known institutes for the HI in Mysore, Bombay and Delhi, who visited the school. Some of them seemed aware of the problem but not very concerned and thought that not much could be done.

I, for my part, continued with my work but with the terrible plight of the children and their families always at the back of my mind. Some families have two and three deaf children and this, coupled with their abject poverty, alcoholic husbands, abandonment and a myriad other social problems is a plight we cannot even imagine. How do they manage?!

What Causes Deafness In India? AIIMS AND JNCASR FINDINGS (2001)

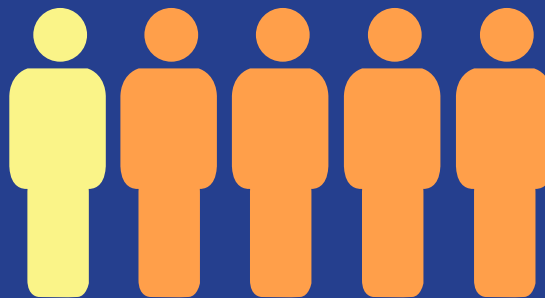
In 2001, there were
84 Lakh ←
deaf people in India.

50% ←
were deaf as a result of
genetic causes



Within the Indian deaf population,

1 in 5
people were deaf because of
consanguineous marriages



Consanguinity is a **social custom**.
So, this cause of deafness can be completely **prevented**.



CONNEXIN 26
on **Chromosome 13**

is the most common gene responsible for
Non-syndromic recessive deafness

the first glimmer of hope

In 1999 – 2000, two things happened that brought a glimmer of light to the end of this dark tunnel !

All India Institute of Medical Sciences (AIIMS), New Delhi had apparently been doing research on this very topic and a research team, headed by Dr. Manju Ghosh, Head of Genetics Unit, Department of Pediatrics, was visiting schools in South India to collect blood samples from the children and their families, for the study and mapping of the genes responsible for causing this type of deafness.

SKID was one of the schools selected for their study.

This is how I met Dr. Ghosh who has been a constant support over the years. She was very happy with the school as all the records were available to the team. Dr. Ghosh told me that when she got back she would do her best to see what could be done to spread awareness about consanguinity and deafness.

Coincidentally, another Institute of high repute, Jawaharlal Nehru Centre for Advanced Scientific Research (JNCASR), Bangalore, was also doing similar research, headed by Dr Anand, and their study material was the entire staff of their Institute along with their families.

Details of their findings, and more statistics on consanguinity can be found on the next page.

deafness due to consanguinity: the numbers



AIIMS findings

Dr Manju Ghosh and her team at the All India Institute of Medical Science (AIIMS) found that:

- CONNEXIN 26 on Chromosome 13 is the most common gene responsible for Non-Syndromic Recessive Deafness.
- These Southern states: Karnataka, Tamil Nadu and Andhra Pradesh have an incidence of 30%, 20% and 20% deafness due to consanguineous marriages.
- National incidence is 20%.

This translates to approximately 6 Lakh persons in a total deaf population of 30 Lakh.

JNCASR findings

An independent study on the same topic undertaken by Dr Anand and his team at the Jawaharlal Nehru Centre for Advanced Scientific Research (JNCASR) had similar results:

- 84 lakh deaf people in India
- Connexin 26 is responsible for 20% deafness in the deaf population of India

This translates to approximately 8.5 lakh persons in a total deaf population of 84 lakh.

statistics and research findings in India

- 52% deafness at the Sheila Kothavala Institute for the Deaf, Bangalore, due to consanguineous marriages. - *Dr Najoo Varkey, Bangalore*
- 40-50% deafness in schools for hearing impaired in South India, due to consanguineous marriages - *G. Kumaramanickavel, a renowned Ophthalmologist from Chennai*
- 50% of marriages are consanguineous in rural areas of the Southern states of Tamil Nadu and Andhra Pradesh - *Dr Ishwar Chander Verma, a pioneer researcher at AIIMS*
- Genetic proof that consanguineous marriages cause deafness provided by two of the country's leading medical and scientific research institutions - AIIMS, New Delhi and JNCASR, Bangalore

government statistics

Health Ministry Data 2005

Total Hearing Impaired	Approx. 29.10 lakh
Due to consanguineous marriages (@ 20%)	Approx. 5.62 lakh

Census 2001

Total Hearing Impaired	Approx. 30 lakh
Due to consanguineous marriages (@ 20%)	Approx. 6 lakh

From the above statistics, compiled by leading Institutes of the country and leading scientists and doctors, it is estimated that **the deaf population due to consanguineous marriages** is approximately **between 6 lakhs and 8 lakhs**.

It is not a figure to be dismissed lightly.



Consanguinity: The Silent Destroyer

A Project by Dr. Najoo Varkey M.B.B.S. M.D. (Pediatrics)

1989-2001: initial study

Consanguinity in parents present among **199 out of 383 children.**

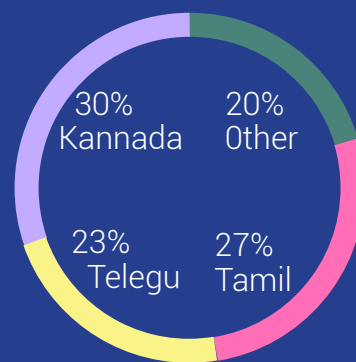
2002-7: further study

Consanguinity in parents present among **82 out of 163 children.**

*this paper was written with the specific purpose of presenting it to the department of disabilities, so it could be used to **spread awareness** on the issue of consanguineous marriages.*

52%

proportion of children who were deaf due to consanguinity; this **remained constant** over 18 years.

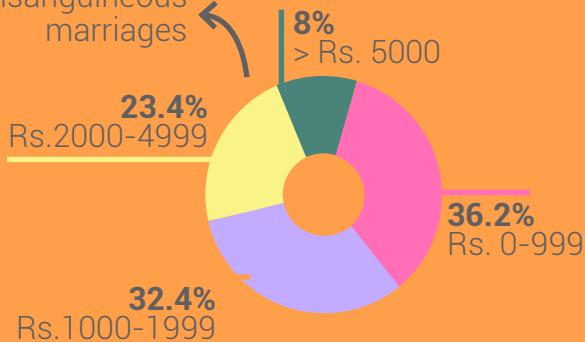


mother-tongue of students from consanguineous marriages

68%

of deaf children from consanguineous marriages came from the **lower income groups** (<1999 Rs.)

monthly income of families with consanguineous marriages



more information can be found in Appendix 1.

a golden opportunity

The second incident that really gave impetus to the project was even more amazing. In January 2000, I was in Bombay. My older daughter, Pervin, had a very bad throat infection and so I took her to my best friend and college mate, Dr. Pilloo Hakim, who was then Professor and Head of the Department of ENT at J.J. Hospital and Grant Medical College. After finishing the check-up we were sitting and talking when my daughter said "why don't you ask Dr. Hakim what you can do?". And Dr. Hakim promptly said "Sure ! If you can submit a paper on consanguinity and deafness by May 2001 to the Association of Otolaryngologists of India and it is accepted by the committee, I will see to it that you can present it at the 54th International Conference of Otolaryngologists of India, to be held at Bangalore in January 2002!"

I could hardly believe this! Finally, after ten long years of "banging one's head against the wall", trying to do something , the opportunity just fell into my lap!

Dr. Manju Ghosh sent me all her research data, and much, much more, to use for my paper. Another good friend and colleague introduced me to Dr. Kaliaperumal, Professor and Head of the Department of Statistics at NIMHANS, Bangalore, who so kindly compiled the statistical data from ALL the medical records that were preserved at the school. This information along with the genetic research of Dr. Ghosh formed the basis of the paper.

Finally, the paper was submitted, as per the deadline, with much help from my family, especially my younger daughter, Navaz and her husband, Anand. At that time (2001 !), I had no knowledge of using a computer and so all the typing and formatting was done by them. The committee accepted the paper.

On 12th. January, 2002 I was able to present the paper at the aforementioned Conference and it was well received.

In hindsight, this really was the start of the campaign for:

spreading awareness to prevent deafness due to consanguineous marriages

(and which continues even to this day).

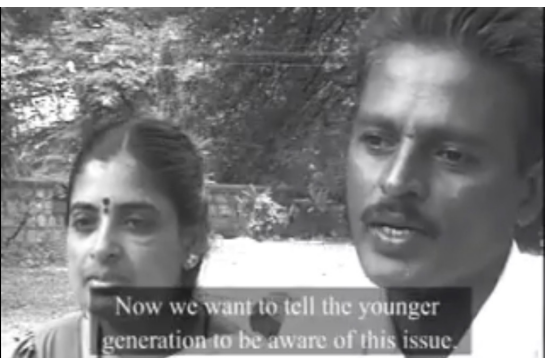
The Awareness Campaign

As part of the awareness campaign, we produced:

- a 15 min. documentary: 'Sound of Silence'
- a 30 sec. spot for audio or video use
- a 1 min. spot for TV

These films are in **English, Kannada, Tamil, Telugu** and are available, free of cost, for spreading awareness.

In 2010 – 11, a voice-over in Kannada was made as a separate CD, the voice being that of Ms. Radha Prathi, a lecturer and also a popular 'voice' at All India Radio. This CD was specially for rural use as Radha explained everything very simply. This is also available free of cost.



screenshots from
'Sound of Silence'

left caption: "now we want to tell the younger generation to be aware of this issue"



raising awareness

The question then arose as to what to do with this information and how to spread awareness. At my request, the School Committee met to discuss this issue. The single most persistent suggestion was - "make a film!", "give it to Doordarshan [government TV network] and your job is done!" It turned out to be a case of 'fools rush in where angels fear to tread !!!'

I got the films made by the internationally renowned film makers Konarak Reddy and Kirtana Kumar. They are old family friends and Kirtana and our daughter, Pervin are also college mates. Also, Kirtana and Kooki make films only on social causes. They put their hearts and souls into this venture and it became a family affair— including the school. The filming took place at SKID & included not only the children but also their parents and teachers.

Written permission had to be taken from the parents to say that they had no objection to being shown on film, along with their children. We were surprised to see that 80% were eager for this - their reason being that **they wanted future generations to know about the harmful effects of Consanguineous Marriages!** This, to some extent, put to rest the belief that these families are totally against change. Something that the powers that be also give as a reason for not spreading awareness.

the films can be found here:

1. the URL: https://www.youtube.com/channel/UCd0_6_Ne-85B1wDsbNh6VQg
2. OR, finding the YouTube account: *Consanguineous Marriages and Disability*
3. OR, directly searching for "*Najoo Varkey*" on YouTube

Advocacy Meetings Held

During 2004 – 2006, besides my work at the school, I personally met:

1. Commissioner and two Assistant Commissioners of Disabilities
2. Two Directors of Disabilities
3. Principal Secretary Women & Child Development
4. Secretary Women & Child Development
5. Two Principal Secretaries Health & Family Welfare
6. Commissioner of Health & Family Welfare
7. Deputy Director Health & Family Welfare, IEC Program
8. Commissioner for Information & Broadcasting
9. Two Directors for Information & Broadcasting in Bangalore.
10. Two Directors, Institute of Speech & Hearing, Mysore
11. Ali Yavar Jung Institute of Speech & Hearing, Bombay
12. Directors of Doordarshan and All India Radio in Bangalore.



advocacy: meetings, meetings & more meetings

Once the films were made we all met again and we thought that all I needed to do was hand them over to Doordarshan and All India Radio and my work was done! Karnataka would wake up to "awareness" every morning and maybe, just maybe, one or two other states also!

This very naïve bubble of inexperience burst immediately.

The 'non-medical', most grueling part of my work had just begun!

Over the next few years, I met many people, and at each meeting I had to explain exactly what I was doing and request them to use the films to spread awareness. Surprisingly, 'Consanguinity' is a vague concept in the minds of most people! I had never done anything like this before and having to do this was something I disliked intensely, as I never knew what kind of reception I would get.

However, the attitude was courteous and friendly in every department that I visited. No one refused outright, to help. All agreed that something needed to be done but that it was a 'delicate' topic regarding age old customs! They accepted the films and said they would definitely try to use them where ever and whenever possible.

But I don't think anything much was done.

The Persons With Disabilities Act Chapter IV (1995)

states the following for the appropriate Governments & local authorities:

1. Undertake or cause to be undertaken surveys, investigation and research concerning the **cause of occurrence of disabilities**.
2. Promote various methods of **preventing disabilities**.
3. Sponsor or cause to sponsor, **awareness campaigns** and disseminate information for general health, hygiene and sanitation
4. **Educate the public** through the pre-schools, schools, primary health centres, village level workers and anganwadi workers
5. **Create awareness** among masses through TV, radio and other mass media on the causes of disabilities and its prevention.



the limits of legislation

The legislation on disability prevention is exemplary, but its implementation is questionable, as is the case with most legislations. The tragedy is that it is the most disadvantaged people with the least resources at their disposal and mostly rural populations, who are the most affected. And, every day, more and more such children are born.

The problem becomes even more tragic when one realizes that **deafness due to consanguinity is one hundred percent preventable.**

No expensive prophylactic drugs –as for measles, hepatitis, polio campaigns etc – are needed. This knowledge and my work at school helped me to keep the campaign going, I guess.

It wasn't a HEAD – ON challenge, aggressive, abrasive. No. It was a subtle, "totally wearing you down" sort of challenge where, in spite of all one's efforts, nothing seemed to happen and so you just wanted to say "that's it !" and forget about it all. But then, something or someone would give a nudge and one found oneself back in the fray! For example, my grand-niece Mishma and her most eloquent request to The Red Elephant Foundation!

spreading awareness is all it takes to save lakhs of children from deafness and



In The News...

For All The Little People Out There

Deccan Herald

September 2009

<https://www.deccanherald.com/content/27225/for-all-little-people-there.html>

Changing Beliefs One Person At A Time

The Red Elephant Foundation

October 2014

<http://www.redelephantfoundation.org/2014/10/changing-beliefs-one-person-at-time.html>

some well-needed advice

Then in October 2009, through Dr. Ghosh, I attended the 4th International Conference on Birth Defects and Disabilities in the Developing World: Translating Research Into Cost-effective Services for Care and Prevention, at New Delhi. One of the delegates was from Brazil, a country very much like India. Her organization was dealing with spreading awareness regarding a particular medical condition.

I quote one of her statements :

“Do not forbid the custom. It is crucial to provide information at appropriate comprehension and literacy levels, and in the context of each family's cultural beliefs and practices. Letting people know that you are interested in what they have to say is vital to building trust.

Martha Carvalho
On Cultural Competency

She and her colleagues lived with the families, followed the above tenets and achieved a lot.

Since 2010 I have been trying to follow her wise words.

So, what I would now advocate is:

1.

Through the Department of Rural Development and also Health & Family Welfare, see if AWs (Anganwadi workers) and ASHAs (accredited social health assistants) can be trained to talk to the people in the houses they visit, about consanguineous marriages and their serious consequences, in a language they understand, without forbidding the same.

The AWs and ASHAs are mostly from the same villages and have a special rapport with the families they visit. They may even have cases of consanguineous marriages in their families with tragic results. So, they would be very effective in spreading the message of the dangers of such marriages. Once sensitized to the issue the people would be much more receptive to messages on radio, TV, village jathres [fairs], loud speakers, street plays, school texts, etc.

2.

The second thing that is very necessary is a **sustained campaign** – over weeks, months and years. Only then will it have any effect. New generations come and even the older ones need constant reminders.

I have received sporadic help in this regard from All India Radio, Doordarshan, the Press, some NGOs etc.

In Nov. – Dec. of 2013, Prajavani, a Kannada daily from the Deccan Herald group of news papers published very relevant articles to coincide with World Disability Day (4 December). Every effort helps and is much appreciated but it needs to be sustained.

The latest help I received is from my grandniece, Mishma, who contacted the Red Elephant Foundation, all on her own, and so this book.

3.

Inclusion and integration of this critical issue in the National Program for the Prevention and Control of Deafness. This should be given the same importance as Chronic Suppurative Otitis Media (CSOM) and Noise Pollution.

4

Spread awareness through as many channels as possible.
A list of these is given below.

● **government**

- Commissionerates and Directorates of Disabilities
- The Department of Woman and Child Welfare
- The Ministry of Social Justice and Empowerment
- The Ministry of Health
- Social Welfare Committees

● **non-governmental organisations**

- Child Rights Groups fighting for the rights of the **unborn child**

● **media (government and private)**

- Television
- Radio (Primary and FM channels)
- Cinema (films / slides)
- Local media - like posters, community loud speakers and wall paintings
- Theatre - especially street theatre in communities

● **community**

- Anganwadi [rural childcare] workers in the ICDS (Integrated Child Development Services) Program
- Village Jathres [Fairs]
- Village Panchayats [local government]
- Primary Health Centres
- Urban and rural Government hospital programs
- NGOs / Social Service organisations

● **education**

Inclusion in the education curriculum via the Human Resources Development Ministry, in:

- Schools and colleges
- Medical Colleges
- Deaf Institutes

spreading awareness works!

In Japan, over one generation, a **widespread awareness campaign** resulted in a **50% reduction** in deafness due to consanguineous marriages.

- XI Congress: World Federation of Deaf (Tokyo, Japan 2-11 July, 1991)

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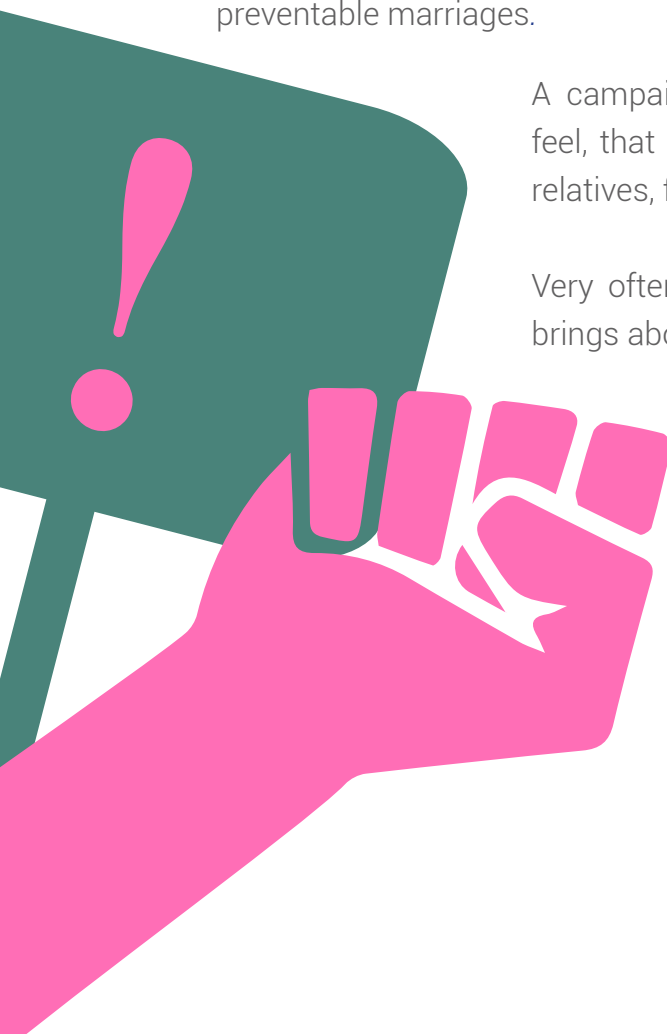
A few years ago, a student at the Bangalore Community College was being pressurized to marry her uncle. Her desire was to continue her education and so was resisting this marriage. At that time, I did my annual session for the students on the impact of Consanguineous Marriages. The young girl immediately got her parents to come and meet the faculty, who were able to explain the hazards in more detail, and **one such marriage was stopped.**

Her story is just one illustration of **what is possible when people are made aware.** And in this case, it cost nothing, but it saved a family.

Therefore, let us act like Japan did, with extreme urgency and very strategically to prevent any more children from bearing the terrible consequences of easily preventable marriages.

A campaign is successful only when the people involved feel, that they themselves, must pass on 'The Message' to relatives, friends and the public at large.

Very often, the personal rapport built by the campaigners brings about this great change !



**One can always
keep hoping for a
miracle!**



Gathering Data: Najoo Varkey with SKID students
Deccan Herald, 2009

**the appendix:
what's left?**

Dr. Najoo Varkey's paper, "Consanguinity: The Silent Destroyer", was written with one specific intention: that it would be presented to the Director of the Department of Disabilities, so that it could be used to **spread awareness** on the issue of consanguineous marriages.

The following pages contain further information from the paper, so that this book might serve the same purpose: **educating all people on the consequences of consanguineous marriages.**

Appendix One includes further literature on consanguinity, and recommendations for action.

Appendix Two outlines efforts taken to spread awareness through audiovisual media, including the "Sound of Silence" documentary, radio and television spots.

Appendix 1: Further Information from "Consanguinity - The Silent Destroyer" (the SKID paper)

There are at least 1000 diseases due to consanguinity and recessive gene transmission. For example, blindness, mental retardation, muscular degeneration, albinism and more recently we are seeing the links between consanguinity and malnutrition.

FURTHER LITERATURE ON CONSANGUINITY'S IMPACT BEYOND HEARING IMPAIRMENT

As Professor M.P. Mathew, a population genetics expert with Kerala University says, "An enormous amount of data has been generated worldwide on consanguinity. The findings have highlighted a spectrum of harmful effects, from minor defects of vision, hearing and speech, to fetal loss and serious disorders, that makes survival beyond childhood impossible".

It is an established fact that:

- Consanguineous marriages are more common in rural areas, though these marriages are prevalent even in affluent educated urban communities where this has been a custom over generations
- Majority of the parents are unaware about the consequences of consanguineous marriages
- Those most devastated by the impact of these marriages are the communities that live in abject poverty and are therefore impacted by other issues related to poverty

In addition, consanguineous marriages can result in children who:

- have a low birth weight to start with
- have immune systems that become compromised
- are often born prematurely
- can have one or more birth defects / disabilities (see section on disability below)

Due to the reasons mentioned above these children are very susceptible to:

- URTI leading to pneumonia that can result in death particularly in undernourished and already weakened children
- GI Tract Infection leading to extreme dehydration possibly resulting in death
- Infectious diseases like measles which in cases of poor families is not treated early leading to complications again possibly resulting in death

child mortality: Attappadi case study

The child mortality cases in the tribal areas of Attappadi may not be just due to malnutrition, starvation or even alcoholism, says population genetics expert P.M. Mathew

It may have a lot to do with consanguinity or inbreeding in humans through marriages among close relatives that is widely prevalent in the tribal areas, says this former professor, one of the first from the state to get trained in human population genetics from the University of North Carolina, many decades ago.

Since then, Mathew and his students have been actively involved in the study of over 40 communities, which allowed marriages among blood relatives. Among these 40 populations studied, at least 14 were tribal populations across the state.

“When closely related persons marry, lethal and sublethal genes from a common ancestor tend to accumulate in the child and cause problems both before and after delivery. Among the tribals in the state, the consanguinity levels vary from a whopping 97.03 percentage among Karuvazhi Pulaya of Idukki. This tribe exhibits the highest rate of consanguinity in the world, it also has a high rate of mortality. The Mudugar tribe in Palakkad, which has a closely-related marriages rate of 78.74 per cent has a high mortality rate of 37.92 per cent,” says the Professor. The mortality studies had revealed a very high rate of 39.04 percentage in the Paniya group, followed by others such as Adiya and Marat.

While debates are on whether it was malnutrition or starvation that caused the deaths of the children in Attappadi, this population expert is of the opinion that such matters as food and alcohol may have contributed, but that the root of the issue is genetic with blood-related marriages down the centuries causing an accumulation of deleterious genes.

You can't give food and wish the problem away. What is needed is genetic counselling and creating an awareness about such risks. The number of close-kin marriages has to be brought down and the age of marriage for women has to be brought up.

additional research on consanguinity

According to B.O. Hanumanthappa, director of the Bidar Institute of Medical Sciences, this is not an isolated case. “Marriage among relatives is common in this region. Children born out of consanguineous marriages have higher risk of having congenital problems. We need to create awareness against this practice,” he said.

Amarnath Solpure, who retired as dean of the Government Medical College in Latur, Maharashtra, said, “This practice is prevalent among landed communities as they want to retain the property within the family. The practice is so common that it has become a part of the culture. This is disturbing.” He observed that children born out of such marriages were more prone to infections and diseases, and lack of neonatal care and malnutrition deteriorates their health further.

“We need to realise that disability and underdevelopment are the price we pay for getting our children married to close relatives,” Lakshmi Kamathane, a member of the anganwadi workers' association, said. She said parents had to share the responsibility with women's groups in the fight against such practices.

A study done at CMC Vellore titled, Foetal Growth and Parental Consanguinity by J.R. Sibert, Malathi Jadhav and S.G. Imbaraj, corroborated the findings of previous researchers. In their study of 322 infants born at CMC Vellore:

- 113 infants were of consanguineous marriages
- 196 were of non-consanguineous marriages

They were studied for parameters of growth i.e. weight, length and head circumference. “Our study

shows that consanguinity contributes to intrauterine growth retardation." Another study by Rao & Imbaraj also from CMC Vellore, showed significant increase in perinatal mortality in infants from consanguineous marriages.

Studies in Japan, Morocco and with Jewish communities have shown similar findings.



VITAL POINTS FOR DISCUSSION AND POLICY-MAKING

Firstly, the problem of disabilities and malnourishment due to consanguineous marriages is 100% preventable. It is simply the result of archaic customs fostered by ignorance, of marriages between uncle/niece and first cousins most common in Southern India.

Customs like child marriage, dowry, sati have been tackled by the State and various governmental and non-governmental institutions through policy, legislation, media awareness and social activism. For example, two major disabilities in India i.e. Blindness due to Vitamin A deficiency and Paralysis due to Polio have had massive public awareness campaigns. Since the Pulse Polio Campaign began in 1988, the effort has cost WHO, UNICEF, Rotary International and the Government a staggering \$ 9 billion till 2013. An additional \$5.5 billion for a six-year (2013-18) eradication plan has just been announced by the WHO.

Eradicating deafness and other disabilities due to Consanguineous marriages which affect hundreds of thousands every year, requires no such prophylactic drugs or expense and yet is not even mentioned in the Prevention of Disability Acts or policy papers.

Secondly, in the future as more and more diseases are eradicated by immunizations etc, genetic disorders like the ones caused by consanguineous marriages, will account for an increasing proportion of death and morbidity.

In the light of this we need to take seriously the rights of the unborn child as stated in the 'Convention on the Rights of the Child' that 'the child, by reason of his/her physical and mental immaturity needs special safeguards and care including legal, not only after birth but before birth also.' Thus, every effort should be made to see that a child is born healthy especially when health problems can be prevented with proper information.

It is therefore vital that the custom of consanguineous marriages be given the same national focus and commitment as the eradication of polio, blindness and also harmful social customs like sati, dowry and child marriage to name a few.



FURTHER LINKS TO RESEARCH PAPERS ON THE IMPACT OF CONSANGUINEOUS MARRIAGES

"Literature review is a critical summary of research on a topic of interest often prepared to put a research problem in context or as the basis for an implementation project."

(Polit and Hungler)

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Appendix 2: Distribution Efforts of 'Sounds of Silence'

As part of the project, a Documentary Film 'Sounds of Silence' and Awareness Spots in English, Tamil, Telegu, Kannada on the issue of consanguinity were made, to spread awareness through multi-media channels. These films, available free for distribution, have so far been given to:

- Commissioner and two Assistant Commissioners of Disabilities
- Two Directors of Disabilities
- Principal Secretary Women & Child Development
- Secretary Women & Child Development
- Two Principal Secretaries Health & Family Welfare
- Commissioner of Health & Family Welfare
- Deputy Director Health & Family Welfare, IEC Program
- Commissioner for Information & Broadcasting
- Two Directors for Information & Broadcasting
- Two Directors of the Institute of Speech & Hearing, Mysore
- Ali Yavar Jung Institute of Speech & Hearing, Bombay
- Directors of Doordarshan and All India Radio

The films can be found here:

1. using the URL: https://www.youtube.com/channel/UCd0_6_Ne-85B1wDsbNh6VQg
2. finding the Youtube account: *Consanguineous Marriages and Disability*
3. directly searching for "*Najoo Varkey*" on YouTube

Listed below, are some of the other efforts to spread awareness using these films.

DISTRIBUTION EFFORTS made since 2002

KARNATAKA

1. Press conferences and interviews to magazines and newspapers
2. Awareness Message and Documentary Film sent to 3 Rotary Clubs in Bangalore
3. 266 CDs of the Documentary Film given to Community Based Rehabilitation Networks, Bangalore for distribution in their centers all over India
4. 2 movie theatres in Bangalore, Santosh and Sagar, showed the Awareness Message (Kannada) for one year - free of cost - from November 2004 to November 2005
5. All India Radio (AIR), Bangalore broadcast the Kannada Audio Message - free of cost – for 8 months, on Akashvani, from February 2005 to October 2005
6. Kannada Audio Message given to the NGO, MYRADA, Bangalore, for their rural radio programme
7. Kannada and English Audio Message given to NGO, VOICES, Bangalore

8. A set of films in Kannada, given to
 - The Commissioner of Disabilities, Bangalore – Mr Krishnamurthy
 - Assistant Commissioner of Disabilities, Bangalore – Mr Pradeep Kumar, followed by Mrs Izzat Begum
 - The Director of Disabilities, Bangalore – Mr Ashok, followed by Mr Shriram Reddy
 - The Principal Secretary, Women & Child Welfare, Bangalore - Mrs Ranjini Sri Kumar
 - The Principal Secretary, Health & Family Welfare, Bangalore - Mr Thangaraj, followed by Mrs Usha Ganesh
 - The Principal Secretary, Information, Tourism & Youth Services, Bangalore – Mr Vittala Murthy
9. Documentary and Television Awareness Message in Kannada given to Doordarshan Kendra, Bangalore
10. A set of films in English and Kannada given to Dr Chandrashekhar Institute of Speech & Hearing, Bangalore
11. Awareness Message in English given to NDTV, Bangalore
12. Audio Message in English given to Radio City 91 FM, Bangalore
13. A set of films in English & Kannada given to the NGO, APSA (Association for Promotion of Social Action), Bangalore
14. A set of films in Kannada and English to the NGO, CRY (Child Rights & You), Bangalore
15. Television Message and Documentary in English and Kannada given to the Director, Rajan Speech & Hearing Centre, Bangalore
16. A set of films in English and Kannada to Social Service Wing, GE India, Bangalore
17. A set of films in Kannada given to All India Institute of Speech & Hearing, Mysore
18. A set of English and Kannada films given to Mr Boroshiva Dasgupta, Director, Manipal Institute of Mass Communication, Manipal, Karnataka
19. A set of English and Kannada films given to Mr Dennis Xavier, Manipal Academy of Higher Education, Karnataka
20. Set of films to the Commissioner, Directorate of Health and Family Welfare
21. A set of films to Additional Director, IDPS
22. A set of films to International Deaf Children's Society (IDCS) through Ms Janani R – Prject Director for Karnataka State
23. A set of films to Mr Mallappa – Founder Samuha – Deaf Project- Kopal – North Karnataka
24. A set of films to a Joint workshop – Voices and IDCS – creating awareness among parents of Deaf children

ANDHRA PRADESH

1. A set of films in Telegu and English sent to NGO, Rural Development Trust (RDT), Anantpur, Andhra Pradesh
2. Radio and Television Message sent to Dr Krishna Rao, ENT Surgeon, Secunderabad
3. A full set of films in Telegu and English given to Mr Ramakrishna, Assistant Director, Doordarshan, Hyderabad, Andhra Pradesh
4. Television Message in Telegu broadcast at main bus terminus and railway station in Kuppam, Andhra Pradesh

TAMIL NADU

1. A set of films in Tamil and English given to Mr K.R.Baliga (IAAS, Retd) Chennai
2. Radio and Television Messages in Tamil and English given to delegates at a Conference on Ethics in Medicine, Madurai, Tamil Nadu
3. Radio and Television Message in Tamil, given to Mrs Jayarani Vijayakumar, Department of Social Science, Lady Doak College, Madurai, Tamil Nadu
4. Radio and Television Messages in Tamil and English given to SAM (Social Action Movement) part of Network and Coordination of Voluntary Organisations, Kanyakumari District, Tamil Nadu

KERALA

1. Awareness Message sent to Cochin, Kerala for Jeevan Television and Alucas (broadcast to USA, Canada and the Gulf region)

MAHARASHTRA

1. A set of films in all 4 languages given to the Director, Dr Rangasayee, Ali Yavar Jung Institute, Bombay

NEW DELHI

1. A set of films in English to Mr Samir Ray, Director, Training Centre for the Deaf, New Delhi
2. A set of films in English given to Mrs Margaret Alva, in her capacity as Secretary of All India Congress Committee (AICC), New Delhi
3. A set of films in all 4 languages given to The Director General of Health Services, Dr. Srivastava, Nirman Bhavan, and the additional Director General, Health Services, Dr. Goyal, Nirman Bhavan, New Delhi. To be used for inclusion in The National Programme for the Control and Prevention of Deafness.
4. Documentary Film "Sound of Silence", screened at the International "We Care" Film Festival, held at New Delhi, between February 20-21 2008. This was for documentary films that dealt only with Disabilities.
5. A set of films in English, given to the Public Service Broadcasting Trust (PSBT), through Mr. Rajiv Mehrotra, Managing Trustee, New Delhi, 2008.

U.S.A

1. A set of films in Kannada and English sent to the Association of Kannada Kootas of America (AKKA) for the World Kannada Conference, held in Washington DC in September, 2006.

**and last but not least,
some very important thank yous...**

acknowledgments

This herculean project which I unwittingly and single-handedly took up would not have been possible without the support I received from my family.

My husband, **Dr Cherian Varkey**'s help was all important as he connected me with several people who were critical to this project. Thank you Cherian!

My younger daughter **Navaz** and her husband **Anand**, had to teach me the ABC's of computers and emails and opened this brand-new world of IT for me. Their untiring guidance and support and encouragement over many, many years has been priceless. Thank you Navaz and Anand!

For the second half of the project, my older daughter **Pervin** was there for me, supporting me with her suggestions and enthusiasm. In her capacity as CEO of CRY (Child Rights & You), she drew on her contacts to help spread the message to a wider audience.

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Ari Rego, my grandson who has always been so encouraging of everything I have been involved with.

When I had shared what my research and association with this project could accomplish, the task of writing the foreword, acknowledgements etc. for this book began. Here, my very sincere thanks and gratitude to **Navaz** who just took over this very time consuming task from me and in the most professional and competent manner, in the space of just two days, put it all together.

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Dr. Manju Ghosh (Retired Head, Genetics Unit, Pediatric Department, AIIMS, New Delhi) who apart from providing all the scientific and genetic data needed for various presentations, became a very dear friend, and through whose good offices I was able to present my paper and films at the 4th International Conference on Birth Defects and Disabilities in the Developing World at New Delhi. I am truly grateful to her for her support and professional inputs which enabled me to extend the scope of this project in many different ways.

Dr Vijayalaxmi Basavaraj (Former Director, All India Institute of Speech & Hearing (AIISH), Mysore), a driving force at the institute, who out of her own interest took my paper and films to use with her students and also for the institute's outreach programs. Later when the institute was appointed the nodal body for the Government of India's initiative, the 'National Program for the Control and Prevention of Deafness' she took my paper and films and personally presented them to the Director General & Assistant Director General of the Department of Health Services, New Delhi, for inclusion in this national program.

Dr Asha Yethiraj (Head of Department, Audiology (AIISH), Mysore) has also been of great help to me through all these years.

Radha Prathi, lecturer and popular 'voice' at All India Radio, who kindly made an audi-visual CD in Kannada for use in rural areas, explaining the consequences of consanguineous marriages.

Dr Sudarshan Ballal (Chairman, Manipal Health Enterprises Pvt. Ltd.) who in May 2016, very kindly approved of providing free medical consultation, examination and investigation for all the children of SKID, and **Dr Niranjana Rai** (Head of Hospital Administration, Manipal Hospital) who oversaw the implementation of this program.

Dr. Piloo Hakim who was such a compelling force through this journey.

Dr. Kaliya Perumal who meticulously sorted through reams of statistical data with such patience and diligence.

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Mrs Asha Dey, a past principal and teacher at SKID, who has been a sincere and keen supporter of the school and the Deaf Aid Society, and deeply committed to all their various activities for over five decades.

Mr Tilak Kumar & Mr K N Shanth Kumar, Deccan Herald, Bangalore who provided the backing of their newspaper to support this project. Mr Shanth Kumar dedicated an entire issue of Prajavani on World Disability Day, Dec 4 2013, to promote the message all across Karnataka.

Deepak Swaminathan & Uday Rao for uploading all the films and creating the 'Consanguineous Marriages and Disability' channel on YouTube.

Once this was done, we needed to create awareness about the channel. It was thanks to **Ms Yasmin Master**, a stalwart of the Deaf Aid Society, who suggested I contact **Mrs Lata Mala** (Department of Women & Child Development) to take on this important task. She in turn, kindly shared the YouTube link with all her colleagues working in the field.

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- **Mrs Indumati Rao** (Director, Community Based Rehabilitation Network)
- **Mrs Mansa Devi** (Department of Women & Child Development)
- **Mrs Janani R** (Head, International Deaf Children's Society, India)
- **Mrs Anita Vasanth**
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- **Vijaya Times, Bangalore** – especially Mr L Ramanand Bhat
- **All India Radio, Bangalore**
- **Door Darshan, Bangalore**
- **Bangalore Club**



Stop Marrying Your Niece! tells the story of Dr. Najoo Varkey's medical activism: her journey to overturn the social custom of consanguineous marriages, which can cause deafness.

As Dr. Varkey explains, **deafness caused by consanguinity is one hundred percent preventable.**

The cure? Education and awareness.

This book aims to be the cure - providing everyone with the knowledge that can help eradicate this harmful custom.

