Thalassaemia Prevention in Sri Lanka

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In Sri Lanka 80 babies with thalassaemia are born every year. They live about 20 years, therefore we have 1600 thalassaemia patients. Each patient needs 100,000-300,000 Rs every year for their drugs alone.
In Sri Lanka 80 thalassaemia babies are born every year.

Why?
What is the reason?

- Nutrition? NO!
- Malaria? NO!
- Infection like dengue? NO!
- Poison? NO!

Marriage between two thalassaemia carries is the only reason for the birth of a thalassaemia patient.
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වේදීම විදිහින් සැමුන්තාවේ දහව්‍රායේ ඉහළක්
විෂ්කයි
High Risk Marriage - داولුකුම් දින් වියපොත්
Thalassaemia Porondama not Matching
නැවේන්වින් කවුරු පුජ රාමු
80 babies with thalassaemia are born as the result of 320 conceptions between thalassaemia carrier couples.

Out of these 320 high conceptions, 160 are 1\textsuperscript{st} pregnancies, and 160 are 2\textsuperscript{nd} pregnancies.

Therefore, we can predict that 160 out of 150,000 marriages per year are high risk marriages.

Those 160 high risk marriages produce 80 thalassaemia babies every year, resulting in 1600 patients and costing 5-7\% of the health budget.
Any other cause for thalassaemia?

Only cause for thalassaemia is the marriage (and conception) between a boy who is a thalassaemia carrier and a girl who is also a thalassaemia carrier.

No! -  නභ
If one of parents is not a thalassaemia carriers non of the children will get thalassaemia disease
Safe marriage - නැවතා දිවියමටේ Thalassaemia Porondama Matching දක්නටම පවතුම් දක්නටම
What is the solution?

Prevent High Risk Marriages

Avoid miss-matched thalassaemia Porondama
Prevent marriages between carriers

Ensure Safe marriages

Match thalassaemia Porondama
Ensure one of the partners in a couple is not a thalassaemia carrier
Do we have other options for thalassaemia prevention?

Yes

Antenatal diagnosis and abortion

Artificial insemination by a donor

IVF of healthy ovum

Gene therapy

Legality?

Acceptability?

Technology?

When?
At present we have only one practical solution!

Prevent High Risk Marriages
Avoid miss-matched thalassaemia Porondama
Prevent marriages between carriers

Ensure Safe Marriages
Match thalassaemia Porondama
Ensure one of the partners in a couple is not a thalassaemia carrier

If not Get ready to look after 1600 or more thalassaemia patients for ever
Is this realistic?
Has any body done this?

Yes - එයි
Pre-marriage diagnosis
Evidence from Iran -- When Abortion was NOT Legalized

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Number of new patients recorded</th>
<th>% of expected without intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before</td>
<td>1200</td>
<td>100%</td>
</tr>
<tr>
<td>1998</td>
<td>480</td>
<td>40%</td>
</tr>
<tr>
<td>1999</td>
<td>416</td>
<td>35%</td>
</tr>
<tr>
<td>2000</td>
<td>341</td>
<td>28%</td>
</tr>
<tr>
<td>2001</td>
<td>206</td>
<td>17%</td>
</tr>
<tr>
<td>2002</td>
<td>78</td>
<td>7%</td>
</tr>
</tbody>
</table>

BMJ 2004;329:1134-1137 (13 November), doi:10.1136/bmj.329.7475.1134
TIF magazine December 2004 Issue No 43 – Iranian Thalassaemia Screening Programme
Iran has done it with out abortions!

BMJ 2004;329:1134-1137 (13 November), doi:10.1136/bmj.329.7475.1134
TIF magazine December 2004 Issue No 43 — Iranian Thalassaemia Screening Programme
What Iran has done!

- Screen Prospective couples -1998
  - Man is tested first
    - if he has microcytosis (MCV <80 fl, MCH < 27 pg)
  - Women is tested
    - If she also has microcytosis
  - Hb A2 is measured (If Hb A2 > 3.5%)
  - Genetic counseling
    - 50% of them have given up marriage!!
    - Others limited the family size

- 2001 – Introduce Antenatal diagnosis
CARRIER DETECTION
JUST BEFORE THE MARRIAGE IS TOO LATE

Therefore carrier screening should be done before a partner for the marriage is selected.

විශේෂ එක් නිවැසයේ ජාතික මාර්ගයේදී උපාදික මොදු
Another successful story
Thalassaemia prevention in Cyprus

دولة قبرص تتخذ إجراءات الوقاية من فرط الهيموسكروبيا المهرة.
What is best for Sri Lanka

Avoiding high risk marriages

High risk marriage = Both partners are carriers

Promote safe marriages

Safe marriage = one of the partners is not a carriers
How to implement?

Prohibition!
Strict rule; marriages between two carriers are not allowed

Expected result?

160 out 150,000 marriages will have to reconsider their proposal

- 50% reduction of thalassaemia births within 2-3 years
- 100% reduction of thalassaemia births within 5-6 years
කේතයක වේදීමේ කැටයම් ගැසීමට දෙකෙක සමාජ වන්නේ සහ මෙමේතුමාව
වලින් වේදීමේ පරිදි කැටයම්
ඔවු 4-5 ම ගැසීමේ කේතයක 100% මේ දුරේ එකම් යනු
How to implement?

Screening at the time of the marriage!
Advice and counsel the couple to reconsider the marriage

Expected result?

160 out 150,000 marriages will have to reconsider their marriage

Difficult situation

Reduction of thalassaemia births depends on the number who will give up the high risk proposal
How to implement?

Screening teenagers and adolescents.

Advice the general public to make a wise decision.

Expected result?

6,000–12,000 carriers will be detected every year. They will have to select a partner who is not a thalassaemia carrier. Only 160 persons will have to consider a second proposal. Reduction of thalassaemia births depends on the number who will follow the advice.
Thalassaemia porondama

Marriage between two carriers;
Thalassaemia porondama not matching

This marriage can have bad effects on their children’s health. 25% of their children will have thalassaemia

If they consider a second proposal chance of matching thalassaemia porondama is 95%
මිය ශ්‍රී ලංකාවේ ආර්ථිකයන්ගේ කටයුතු විශේෂ

මිය ශ්‍රී ලංකාව විශේෂය සංස්කරණය සැතින්නේ අන්ද.

මාර්ගය දක්වන මතකට ආර්ථික කටයුතුව කෙරුණායක වේ,

ත්ව කොටසය දෙක්, ආයාතය කොටසය පෙන්නායක.

මිය දුරු කොහොමද මතන්. ආර්ථිකයන්ගේ කටයුතු සැකසේකත්වය අවසන්න මුළු වලින් ප්‍රකාශය කළදා විශේෂ 25% මත, ආයාතය දෙක්ම ආර්ථිකයන් කටයුතුව පෙන්නායක.

විදේශ විශේෂව විශේෂ කොහොමද. ආර්ථිකයන්ගේ කටයුතු මේවාවන්

පිට 95% ක් කොටසයකි
අධීක්‍ය ප්‍රශ්නයන්

මහත්වයක් වේගන්තික ප්‍රශ්නයන් සමාගමේ අධීක්‍ය ප්‍රශ්නයන්, ඔවුන් පිළිතුරු සඳහා මෙන්ම මෙම්මි නො පිළිතුරු.

මනාවක් ප්‍රශ්නයන් පිළිතුරු මෙන්ම මෙම්මි නො පිළිතුරු

100% මෙතේ පිළිතුරු

දුළ අතරි!

මෙම්මි ප්‍රශ්නයන් හා ප්‍රශ්නයන් පිළිතුරු මෙම්මි නො පිළිතුරු මෙම්මි නො පිළිතුරු.
Thalassaemia Porondama

If one of the proposed couple is a thalasaemia carrier, the other person is NOT a carrier. that proposal is safe. This is a safe marriage

Non of the children will be affected by thalassaemia

Wish them a happy marriage!
But remember to check their siblings and their children for thalassaemia when they consider marriage
What can we do?

Educate the public

What?

Having a baby with thalassaemia is difficult situation

What can we do?

Educate the public

What?

Having a baby with thalassaemia is difficult situation
What can we do?

Educate the public

Thalassaemia can be prevented
What can we do?

Educate the public

What?

Any body may be a thalassaemia carrier

You never know unless you check your blood
What can we do?

Educate the public

Facilities for blood test is available!
Any medical officer can advice what to do

Facilities for blood test is available!
Any medical officer can advice what to do
What can we do?

Educate the public

What?

Avoid marriages between two carriers

What?

The society should encourage giving up high risk proposals
What can we do?

Educate the public

By Whom?

Health care professionals (HEB, FHB, Ministry of health)

Teachers (ministries of education)

Community leaders

Politicians

Media Personal

Radio, Television, News papers, others
How to Implement thalassaemia Porondama

• Education
• Monitoring
• Re-enforcement
Education for thalasaemia prevention

- Health care professionals
- Ministries of Education and Higher Education
- Media personal
- Registrars of marriages
- Marriage brokers (match makers, kapuwa)
- Horoscope readers
- Community leaders (Gramasavaka, Samurdhi niladari,...........)
Education for thalassaemia prevention

Target is to change the attitudes of the society with regards to decision making in selecting a partner for marriage

• Inclusion of the message in the school curriculum
• Insert a question for O/L or A/L papers
• Teledrama
• Certificate course for horoscope readers and marriage brokers
Monitoring and reinforcement

- Screening by PHM
- High risk Marriage by registrars of marriage
- High risk Pregnancies by VOG
- Births of thalassaemia babies by Pediatrician
My request

Help thalassaemia carriers who don’t know that they have a major problem ; The risk of having a baby with thalassaemia

Educate thalassaemia carriers that they have the risk of having a baby with thalassaemia unless they marry some who is not a carrier
Thalassaemia Prevention is a responsibility of every body in the society
What is the national thalassaemia prevention policy

• Teenage and adolescents voluntary screening
• Counseling
• Promote safe marriage
• Monitor
  – high risk marriages by registrar of marriage
  – High risk pregnancies by VOG
  – Births of thalassaemia patients Pediatrician
Thalassaemia Prevention in Sri Lanka
Thank you