

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 need 100 000- 300 000 Rs
every year for their drugs alone

In Sri Lanka 80 thalassaemia babies are borne every year

Why ?

What is the reason ?

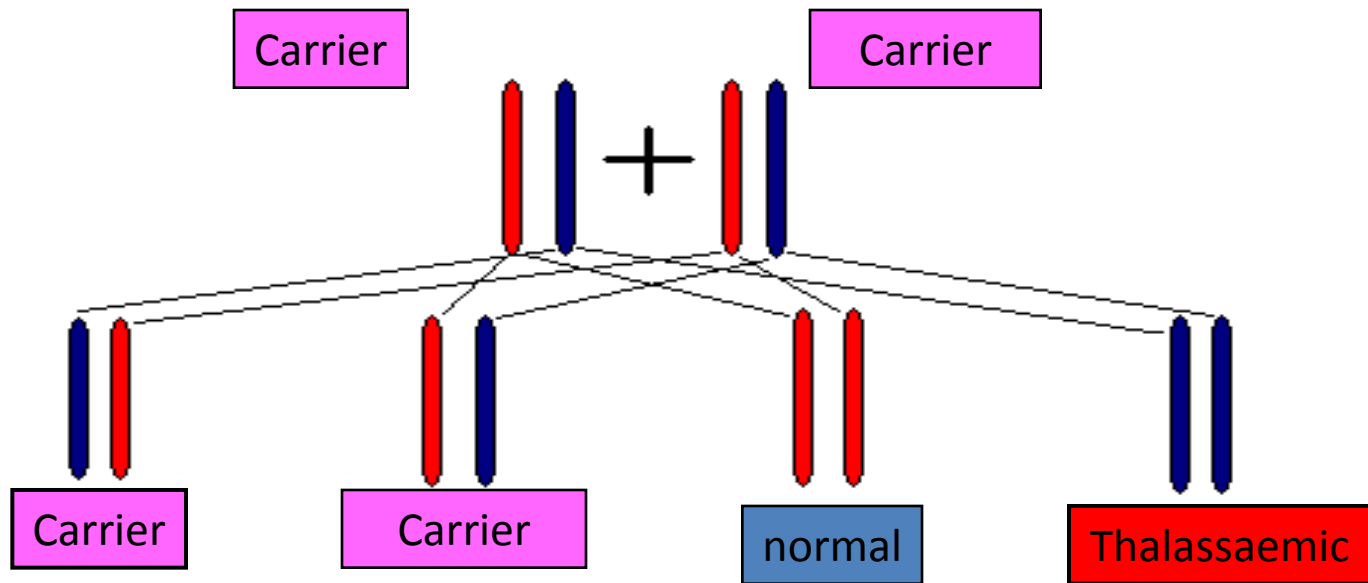
Poison ?

NO!

Marriage between two thalassaemia carries is the only reason for the birth of a thalassaemia patient

නැලඹීමේයාවෙන් පෙලෙන දරුවෙකු බිහිවීමට
ඇති එකම හේතුව
නැලඹීමේයා වාහකයින් දෙදෙනෙකු අතර සිදුවන
විවාහයයි

සියළුම නැලඹීමේයා රෝගීන්ගේ මවන් පියන් දෙදෙනාම නැලඹීමේයා වාහකයින්ය



High Risk Marriage - අවදානම් සහිත විවාහයක්

Thalassaemia Porondama not Matching

තැලසීමියා පොරොන්දුම නොගැලපේ

80 babies with thalassaemia are born as the result of 320 conceptions between thalassaemia carrier couples

Out of these 320 high conceptions 160 are 1st pregnancies 160 are 2nd 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 1600 patients and costing 5-7% of health budget

Any other cause for thalassaemia ?

තැලෙසීමියා රෝගියෙකු බිහිවීමට වෙනත් හේතු තිබේද?

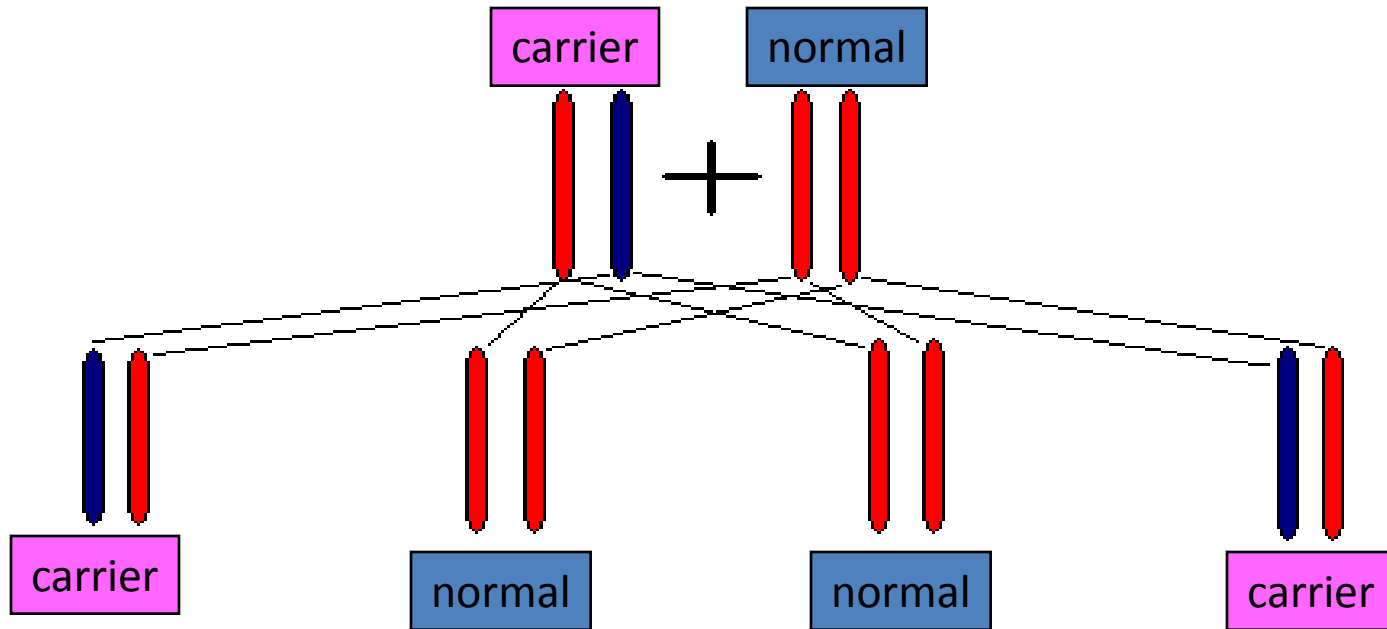
NO ! - නැත

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

තැලෙසීමියා වාහක පිරිමි දරුවෙකුත් තැලෙසීමියාවාහක ගැහැනු දරුවෙකුත් අතර වන විවාහය (දරුඵල ලැබීම)
තැලෙසීමියා රෝගියෙකු බිහිවීමේ එකම හේතුවයි

If one of parents is not a thalassaemia carriers non of the children will get thalassaemia disease

විවාහ වූ පෝඝුචක මව හෝ පියා දෙදෙනාගෙන් එක් අයෙකු වත් තැලෙසීමියා වාහක නොවේ නම් එම දෙපලට දාව උපදින කිසිම දරුවෙකුට තැලෙසීමියාව නොවැලඳේ



Safe marriage - ආරක්ෂාකාරී විවාහය
 Thalassemia Porondama Matching
 තලෙසීමියා පොරොන්දුම ගැලපේ

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

Legality?

Artificial insemination by a donor

Acceptability?

IVF of healthy ovum

Technology?

Gene therapy

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 t look after 1600 or more thalassaemia patients for ever

Is this realistic?

මේ අදහස යතාර්ථවාදීද?

Has any body done this?

මේ වැඩේ කවුරුහරි කරලා තියනවද?

Yes - ඔව්

Pre-marriage diagnosis

Evidence from Iran -- When Abortion was NOT Legalized

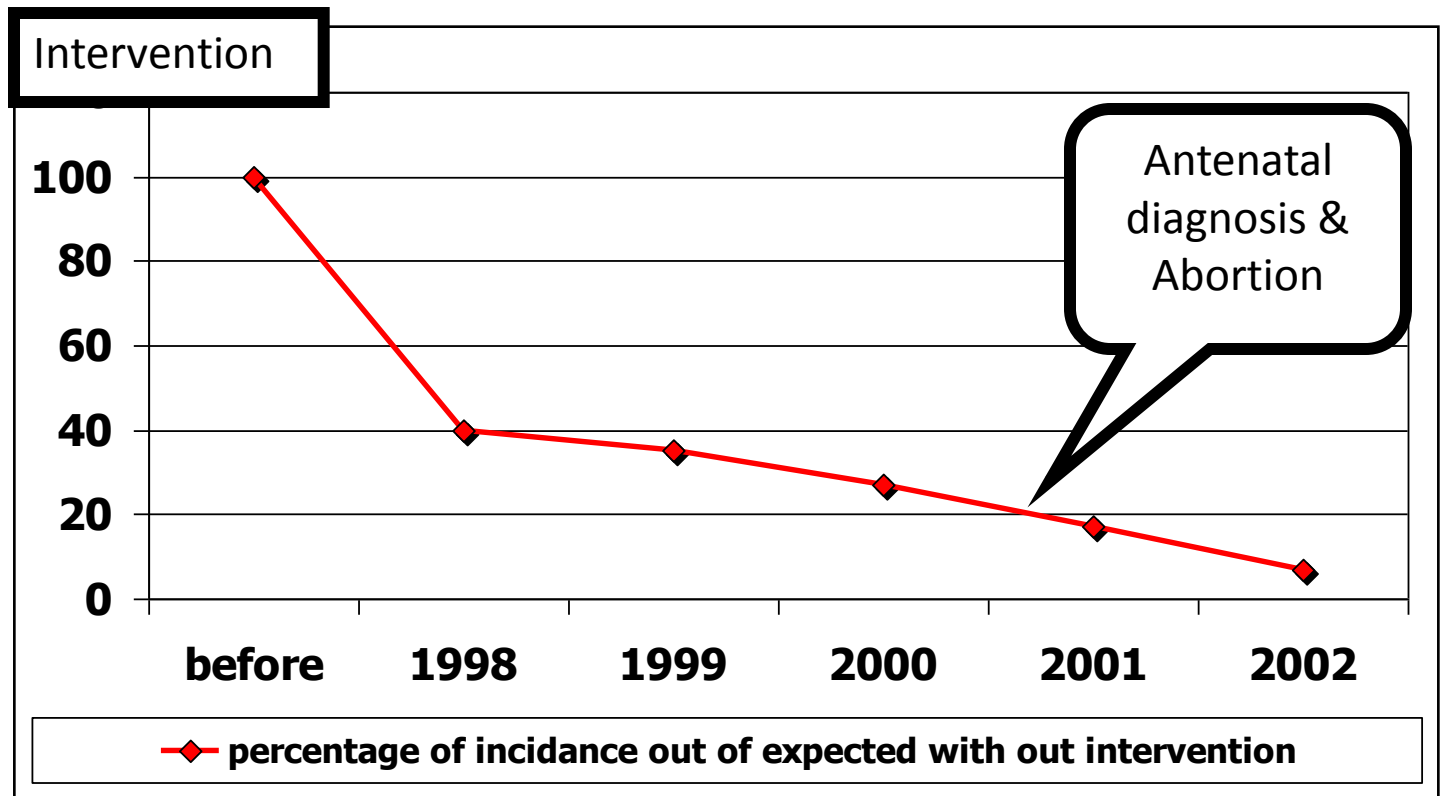
Year of birth	Number of new patients recorded	% of expected with out intervention
Before	1200	100%
1998	480	40 %
1999	416	35%
2000	341	28%
2001	206	17%
2002	78	7%

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

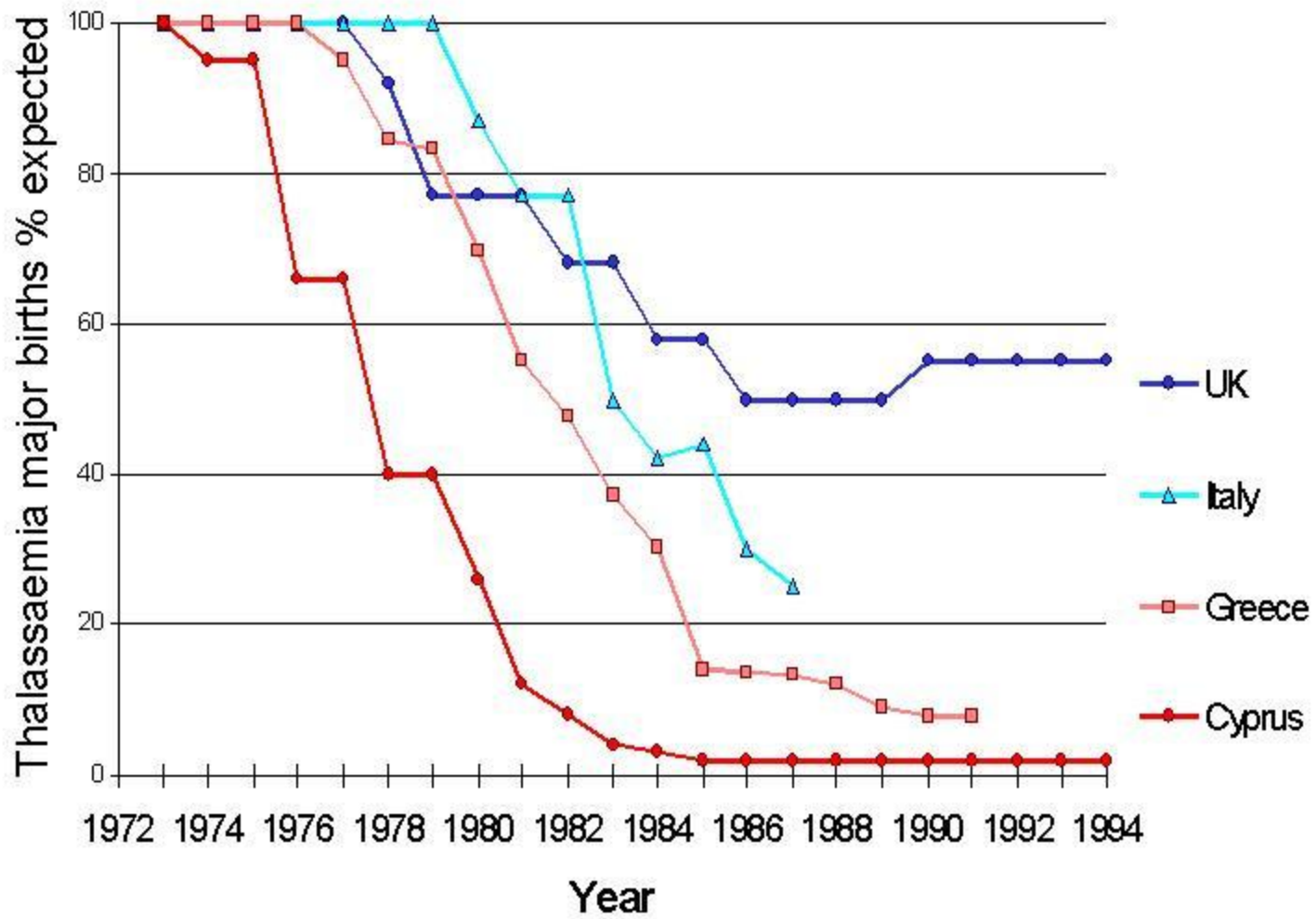
විවාහ වන දිනයේ වාහක බව දැනගැනීම පමා වැඩිය

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

වාහක බව දැනගත යුතු වන්නේ සහකරුවෙකු සොයා බලන යෞවන වයසේ දීය

Another successful story

තැලෙසිම්යාව චලකවා ගැනීමේ තවත් සාර්ථක කතාවක්



Thalassaemia prevention in Cyprus

සයිප්‍රසයේ තලෙසීමියාව වලක්වා ගැනීම

ΙΔΡΥΜΑ ΜΑΚΑΡΙΟΥ Γ΄
ΚΕΝΤΡΟ ΘΑΛΑΣΣΑΙΜΙΑΣ
ΓΝΩΜΑΤΕΥΣΗ
Η εργαστηριακή έρευνα έδειξε:
ΕΤΕΡΟΖΥΓΟΣ Β' ΜΕΣΟΓΕΙΑΚΗ ΑΝΑΙΜΙΑ
Ο Ιατρός
(Form Med. 232)

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ΚΥΠΡΙΑΚΗ ΔΗΜΟΚΡΑΤΙΑ
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ΚΕΝΤΡΟ ΘΑΛΑΣΣΑΙΜΙΑΣ

Β Ε Β Α Ι Ω Σ Η

Βεβαιούται ότι

ο/η
από
αρ. Ταυτότητας, έχει εξεταστεί για τη
Μεσογειακή αναιμία και του/της δόθηκαν οι κατάλληλες συμβουλές.

Ο Ιατρός

Ημερομηνία

Το παρόν πρέπει να παρουσιάζεται κατά την έκδοση άδειας αρραβώνων ή γάμου.

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

තැලෙස්මියා වාහකයින් දෙදෙනෙකු අතර වන විවාහයන්
වලක්වාලන තහනමක් පැනවීමෙන්
වසර 4-5 ක කාලයක් තැලෙස්මියාව 100% ක්ම තුරන් කල හැක

විවාහයක් අනුමත කිරීමට නම්
යෝජිත පෝද්වක එක් අයෙකුමත්
තැලෙස්මියා වාහක නොවන්නට වග බලාගත යුතුය

වසර 4-5 ක කාලයක් තැලෙස්මියාව 100% ක්ම තුරන් කල හැක

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

Advice the general public

Exp

6 000

They will

detected every year

who is not a thalassaemia carrier

have to consider a second proposal

Red

thalassaemia births depends on the number who will follow the advice

Thalassaemia Porondama
Thalassaemia Porondama

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%

මේකට කියන්නේ තැලෙසීමියා පොරොන්දුම කියලා

මේක නොසලකා හරින්නට බැරි බොහොම බලගතු පොරොන්දුමක්

තැලෙසීමියා වාහක දෙදෙනෙක් විවාහ වෙන්න යෝජනා කෙරෙනවා නං,
ඒ යෝජනාව අශුභයි, දරුවන්ට අශුභඵල ගෙනෙනවා.

මේක සුලු කොට තකන්නට එපා. තැලෙසීමියා පොරොන්දුම නොගැලපෙන
පෝඤ්චකට දාව උපදින දරුවන්ගෙන් 25% ක්ම , දරුවන්ට අශුභයි
තැලෙසීමියාව වැලඳෙනවා.

වෙනත් යෝජනාවක් සලකා බලන්න. තැලෙසීමියා පොරොන්දුම ගැලපෙන
බව 95% ක් විස්වාසයි

තැලෙසීමියා පොරොන්දුම

ශෝඡනා කෙරෙන ජෝඩුවෙන් එක්කෙනෙක් තැලෙසීමියා වාහක , අනෙකා වාහක නොවෙයි මේ ශෝඡනාව නං ශුභයි,

තැලෙසීමියා පොරොන්දුම ගැලපෙන ජෝඩුවකට දාව උපදින දරුවන්ට තැලෙසීමියාව වැලඳෙන්නේ නෑ කියල 100% කම විස්වාසයි.

ශුභ මංගලම්!

සහෝදර සහෝදරියන්ගෙන් ඔයගොල්ලන්ගෙ දරුවන්ගෙන් තැලෙසීමියා පොරොන්දුම බලන්න අමතක කරන්න ඒපා.

Thalassaemia Porondama

If one of the proposed couple is a thalassaemia 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

තැලසීමියා රෝගයෙන් පෙළෙන දරුවෙකු බලා ගැනීම සුළු පටු වැඩක් නොවේ

What can we do?

Educate the public

What ?

Thalassaemia can be prevented

තැලෙසීමියාව වලක්වා ගත හැකිය

What can we do?

Educate the public

What ?

Any body may be a thalassaemia carrier

You never know unless you check your blood

ඕනෑම පුද්ගලයෙකු තලෙසීමියා වාහකයෙකු විය හැක

ලේ පරීක්ෂාකර ගන්නාතෙක් එය හඳුනා ගත නොහැක

What can we do?

Educate the public

What ?

Facilities for blood test is available!
Any medical officer can advice what to do
ලේ පරීක්ෂා කර ගැනීම සඳහා පහසු කම් තිබේ
ඕනෑම වෛද්‍ය වරයෙකු මේ පිලිබඳව උපදෙස් දිය හැක

What can we do?

Educate the public

What ?

Avoid marriages between two carriers

වාහකයින් දෙදෙනෙකු විවාහවීමෙන් වැළකිය යුතුය

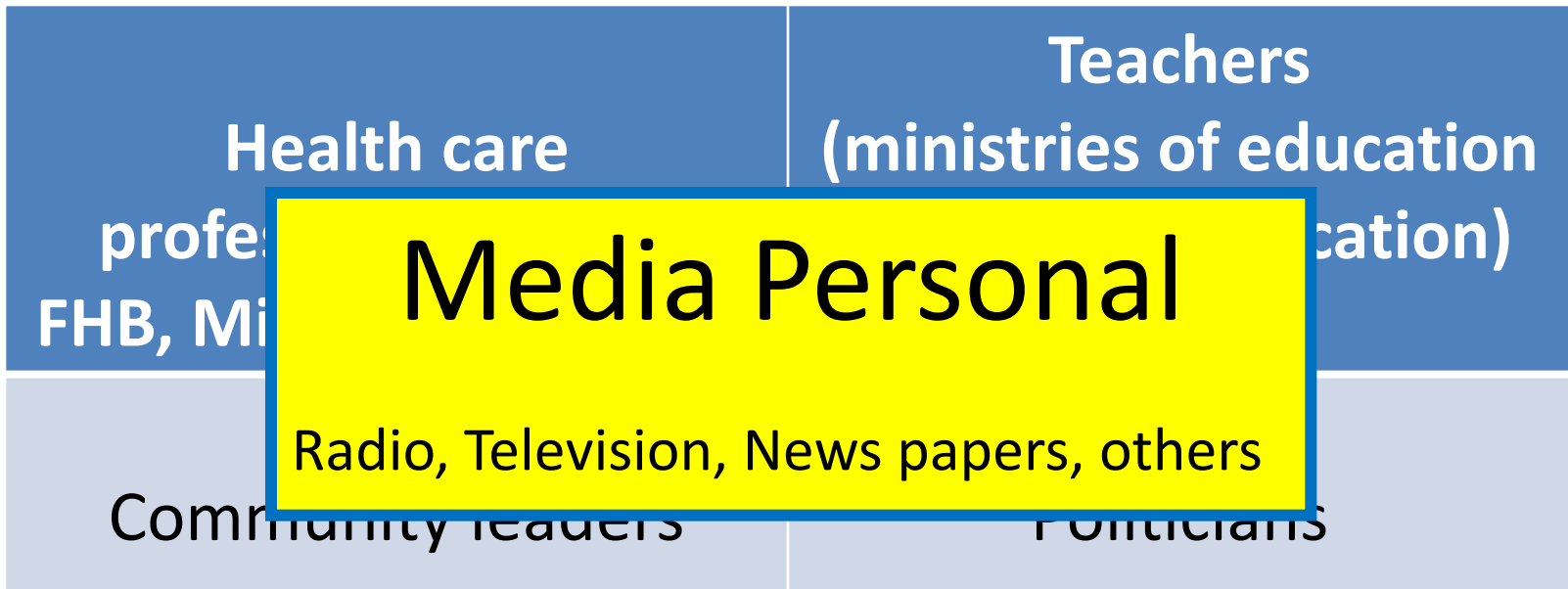
The society should encourage giving up high risk proposals

වාහකයින් දෙදෙනෙකු අතර විවාහ යෝජනා අතහැර දැමීමට සියළු දෙනා අනුබල දිය යුතුය

What can we do?

Educate the public

By Whom?



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 someone who is not a carrier

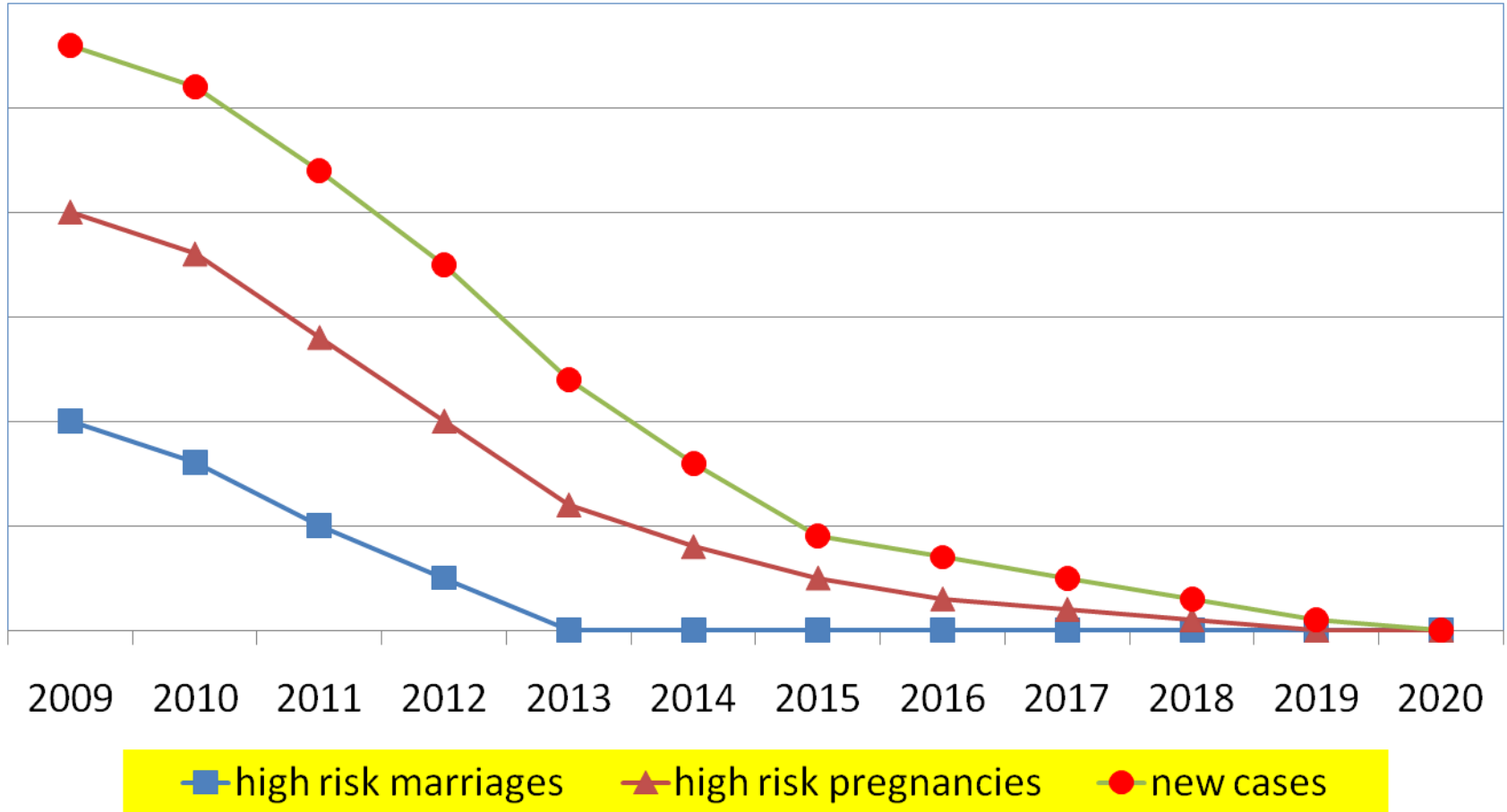
Thalassaemia Prevention is a
responsibility of every body in the
society

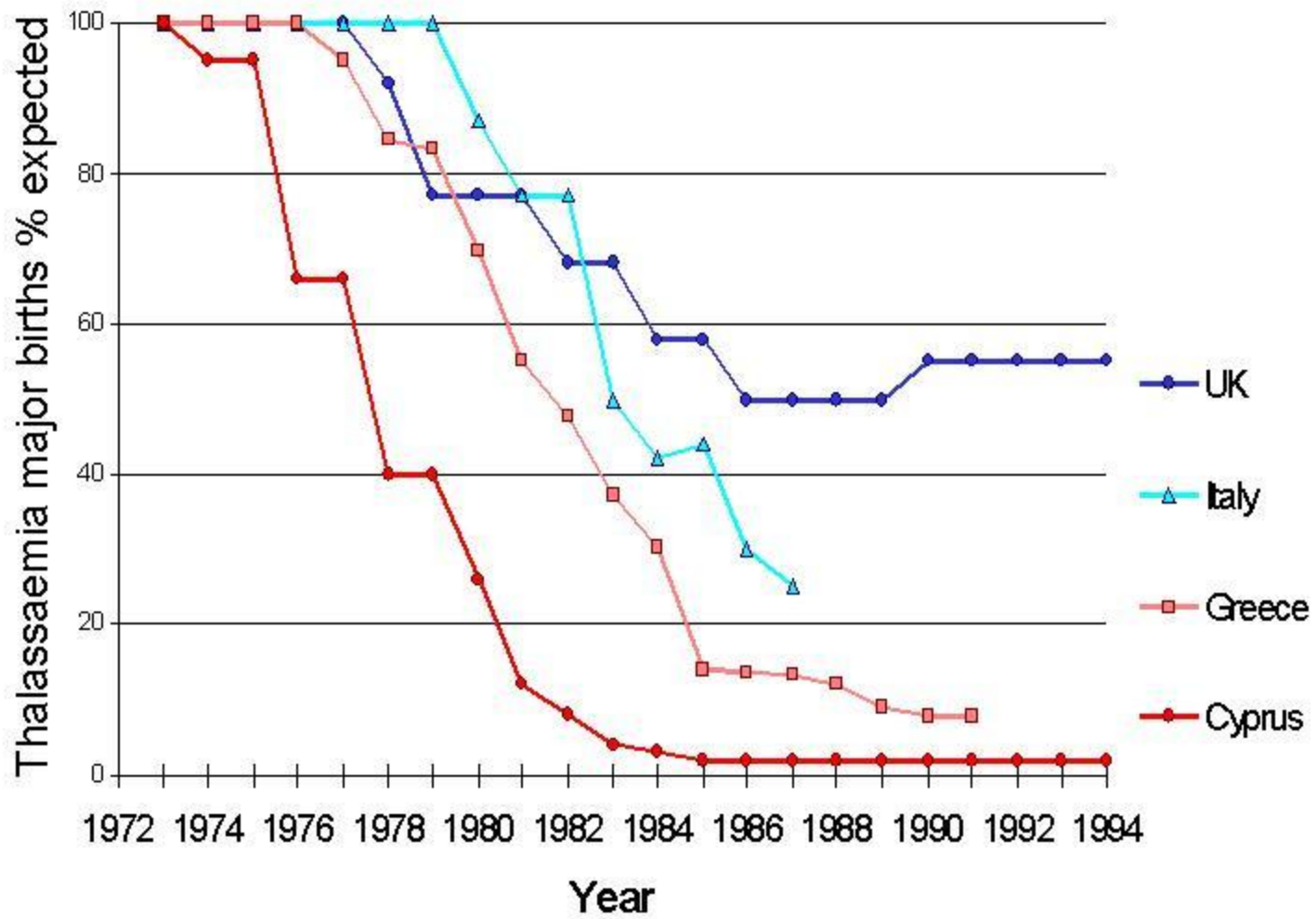
තැලසීමියාව වළක්වා ගැනීම සමාජයේ සියළු දෙනාගේම වගකීමයි

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