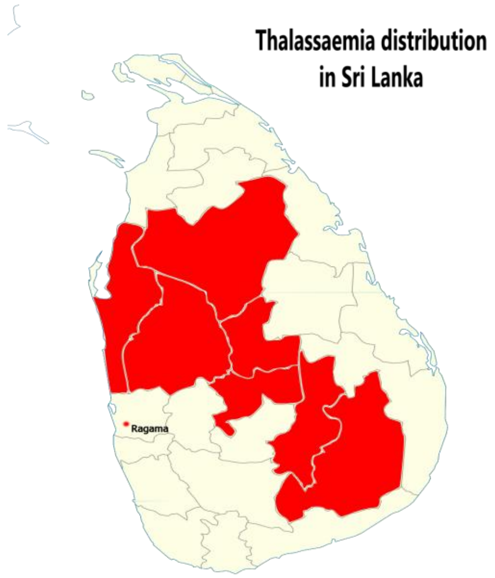
“Hemals”Adolescent and Adult Thalassaemia Care Unit
North Colombo Teaching Hospital (RAGAMA)
Sri Lanka

The Adolescent and Adult Thalassaemia Care Unit North Colombo Teaching Hospital ,Sri Lanka

The Democratic Socialist Republic of Sri Lanka is an island situated in northern Indian Ocean in South Asia. Sri Lanka is a diverse country with 21 million people of many ethnicities, practicing many religions and speaking many languages, making it their home. It has a total area of 65610 km^2. For administrative purposes the country is divided into 9 provinces and 25 districts.

Sri Lanka has been identified as a country which has an intermediate prevalence of thalassaemia and up to date around 3500 patients affected with the disease have been identified. The majority of them have beta thalassaemia major whilst a third have Hb E beta thalassaemia.

The first Thalassaemic patient in Sri Lanka was reported in 1952, but until 1995 there was no proper management of them mainly due to the lack of knowledge about thalassaemia and insufficient motivation amongst the medical professionals. Since 1995 the interest shown in the management of thalassaemia has improved remarkably unquestionably due to direct and indirect contributions made by Prof. Sir David Weatherall.



Studies done in 1997 and 2009 show that the distribution of thalassaemia within the country is unequal. It is highly prevalent in North West province, North Central Province and Central Province.

The first ever dedicated thalassaemia centre in Sri Lanka was established in Kurunegala in 2002, and besides this exception most patients with thalassaemia are managed in general pediatric wards. After about 2009 a few other dedicated thalassaemia centers which manage children with the disease have been established in a few hospitals.

Since 1995 all thalassaemic patients were exempted from the requirement of finding donor replacements for blood transfusions and this considerably improved the quality of care for thalassaemics in Sri Lanka. As per National Health Policy all medications including blood and chelating agents are available free of charge for all patients in the country. With increasing awareness about the advances in thalassaemia management amongst the medical profession more and more pediatricians have taken an active interest in the management of these patients.

As a result of these advances the number of thalassaemics living into the 2nd and 3rd decades of life has started to increase. However, the adult physicians in the country just like many in the rest of the world are still not involved in the management of these patients who are transcending the pediatrics age group. It is in this background that we set up the first ever unit dedicated to the management of adolescent and adult patients with thalassaemia in Ragama a township which is situated just 15 km north of Colombo.

North Colombo Teaching Hospital - Ragama

In 2006 February the Adolescent and Adult Thalassaemia Care Unit was established in the North Colombo Teaching Hospital with the objective of providing better qualitative standardized care for adolescent and adult thalassaemic patients in the country.

At present the thalassaemia services we provide cover three facets. They include the Adolescent and Adult Thalassaemia Care unit, an HPLC based Thalassaemia Diagnostic haematological Laboratory, and a molecular genetics laboratory which specializes in thalassaemia diagnostics.

Adolescent and Adult Thalassaemia care unit

In 2002 August Dr Anuja Premawardhena then a lecturer attached to the Department of Medicine of University of Kelaniya, also working in the North Colombo (Teaching) Hospital Ragama returned from the UK after having completed a D.Phil from the University of Oxford working under Prof Sir David Weatherall. In Oxford he trained in thalassaemia genetics and also did a collaborative clinical study on patients with Hb E beta thalassaemia. His general training was in internal medicine and thalassaemia and haematological disorders was his sub specialty. As he was a specialist attached to the professorial medical unit of the North Colombo teaching hospital he was immediately responsible for looking after the few thalassaemia patients attending the unit. The numbers were few but the level of care for these patients was really pathetic.

Being managed in a busy acute medical care unit, these adolescents were largely neglected. Most of the time the patients were in the ward for 3 to 5 days to receive the transfusions and chelation was restricted to intravenous chelation during the time of transfusion. Only one out of the 6 patients had an infusion pump for themselves. Most of the time they did not have access to a hospital bed as the beds were already occupied by acutely ill patients. The thalassaemic patients were traumatized with the many inquiries from inquisitive patients and bystanders, especially regarding the need for transfusions and queries about their abnormal facial features.

The need for a specialized unit was very clear but the logistics of setting up a unit in a multi specialist acute care medical ward seemed insurmountable. After having convinced the then Head of Department of Medicine about the need, he and the ward sister Mrs. Asoka Wickramasinghe, who was already on board for the mission, set about finding a suitable space. The only available space was a 10x10 foot room which was being used as dump to store rejected and condemned equipment from the medical ward.

Our vision was to build a home away from home for them as they had to come to hospital frequently for blood transfusions. Our main objectives were to make the hospital stay of the patients as short and as pleasant as possible and to make the unit function mainly as a day care unit. By setting up a specialized unit we were sure we could improve the quality of care mainly by optimizing blood transfusions and iron chelation therapy. And we knew that the need for such a unit for adults with thalassaemia was very pressing and the numbers patronizing the unit was very likely to increase.

Setting up of the unit was a struggle. It was a time when there was no recognition or national policy for thalassaemia management by the government. Though we had identified a space to start the unit we needed approval from the hospital authorities to start a new centre, though it was to function merely as an ancillary unit of the Professorial Medical Unit. This was necessary as we needed equipment and staff. Sadly the concept of a separate unit for a few patients with Thalassaemia was not even considered by the hospital administrators as practical or even necessary. Especially so as the tertiary care hospital was already struggling for space even for more essential hospital units. We had to convince the authorities that we will not be a drain of the already limited resources of the hospital and also had to convince the hospital administration that we would ourselves find the space, which we had already done!! Most of the funding for furnishing the new unit came from a few well-wishers and within 3 months of the initial planning we converted the dump store to the first ever "Adolescent and adult Thalassaemia care unit" of the country! We intentionally used the word "care" in the name as that was what we intended to do! It was not going to be just another hospital unit which had beds, doctors and nurses: we were truly going to look after these people.

We also wanted to have as few beds as possible as we were not necessarily dealing with ill people, and instead used a few comfortable sofas (just 6 of them) which could be doubled up as transfusion chairs. The hospital administrators who were initially skeptical of our ambitions helped us by air conditioning our room, which was essential as the room did not have good ventilation. There were no doctors or nurses specially attached to the unit; instead we were able to convince the ward sister of the female general medical unit to allow one of her nurses to oversee the work. Sadly there was no separate toilet for the unit so the patients had to continue to use the very crowded and badly kept ward toilets.

The first ever medical officer was barely out of her university and a parent and the consultant jointly split the cost of her salary for the first few months. We had already secured research funding from the UK for clinical research that we did and we were able to siphon out a little bit of money from that, with the permission of the awardees for the up keep of the unit.

The opening of the unit was attended by the hospital director and the Dean of the Faculty of Medicine of University of Kelaniya who also was rather conveniently the Chair Professor of Medicine who supported us immensely.

At the opening ceremony of first adult and adolescent thalassaemia unit in teaching hospital premises.

The advancement of our unit over the last 6 years has been truly remarkable. Being situated in an area in Sri Lanka where Thalassaemia is not widely accepted to be common, we started attracting many patients from different parts of the country. By the end of the first year itself we had quadrupled the number of patients in the unit and six years after inception we now serve over 286 patients , the second largest number of thalassaemia patients in the country! Though the hospital policy was to cater to the patients only from the province we decided not to abide by the protocols and opened it up to any one with the need.

As a result of very cordial relationship with administrators and other sectors of hospital staff we made sure that our patients never ran out of chelators, a perennial problem in most other units in Sri Lanka. In the few instances that the drugs were not available in the government stores we were able to rope in the help of pharmaceuticals to get the necessary drugs free of charge in the interim.

We conducted seminars for patients and parents about the need for compliance and were truly surprised that most of them were not well clued about the need for having low iron levels or even the need for having regular transfusions. It was clear that most parents had not being properly briefed about the disease even after living with a child for a dozen years!

The unit was an instant success. The patients for the first time in their lives had a decent place to receive treatment. Despite the many limitations, patients and the parents were truly happy. The tremendous response urged us to do more and more for them. The predictable sequel to all this was that the unit began to attract more and more patients.

The more patients came the more problems we had in accommodating them. The Unit which was meant to deal with 20 patients at most now had to cope with sometimes even 30 patients a day. As most patients, even adults came with at least one parent it meant that we had to host almost 60 people in this tiny cubby hole! We desperately needed more space or had to put a stop to recruiting more patients. The latter option was unthinkable but finding a new place was next to impossible. We thought of raising our own money to build a bigger unit but the idea was still born as the funds needed could not be raised. Our luck finally changed in 2011 February. A lady had expressed her wish to donate a three story building she owned to the hospital. The building was situated 10 km away from the main hospital complex and there were very few doctors in other specialties who were interested in making the extra trip. That turned to be our opportunity as we literally jumped at the offer of using this for our thalassaemics.

When we visited the place we found that it was in a dilapidated state and knew that it would take a lot of renovation and refurbishment before it was made habitable. It was just a hall with no rooms or a proper ventilation system. We had to build a medical ward from scratch, and the present hospital director Dr Roy Perera made use of his influences to get finances from the Health Ministry of Sri Lanka to convert the run down building into a state of the art ward complex.

The hall, then

After the renovation and refurbishment

Moving away from the teaching hospital premises was not an easy task as we had to function as an independent unit. We had to allocate nursing officers and other employees such as sanitary workers for this unit separately. We didn’t want this unit to be a burden to any staff members so we welcomed those who came to us willingly

With 5 nursing officers and one medical officer, we moved to our newly renovated and refurbished spacious building on 11.11.2011

The opening ceremony of the "Hemals" thalassaemia center with the donor and well wishers

The unit was set up in two floors, having the inward treatment and care in the first floor, Laboratory , Auditorium and the vocational training center on the second.

The auditorium

the vocational training center

Separate male and female cubicles with beds were built. Comfortable beds, mattresses and linen were provided by the teaching hospital Ragama. The newly built wards had wider windows and doors that allowed sunlight and fresh air to move into the wards freely. We felt that our patients were enthusiastic and exited about their new home as they came up with their own creative ideas on what more could be done to make this place homely.

The Male ward

The Female ward

Nurses' Station

Most of our patients travelled from far and it was necessary for them to stay overnight until the blood transfusions and medical treatment was over. It was necessary to have a dining hall as well as a kitchen in the premises as they could prepare the food of their choice with the help of the care givers or their parents. With this thought, a separate kitchen with continuous supply of water, gas and food was built in. Even though the meals are provided from the teaching hospital daily, they preferred to prepare their own food and drinks according to their wishes. To add a difference to their meal, with the help of well wishes and friends, we made a system that would allow donors to bring in special meals such as short eats, cakes, sweets and other fancy foods which are not in their usual daily menus.

Our kitchen and dining area

Indoor games such as carom, checkers and board games were kept in premises with easy access to them. They were encouraged to take part in these games to prevent boredom and loneliness.

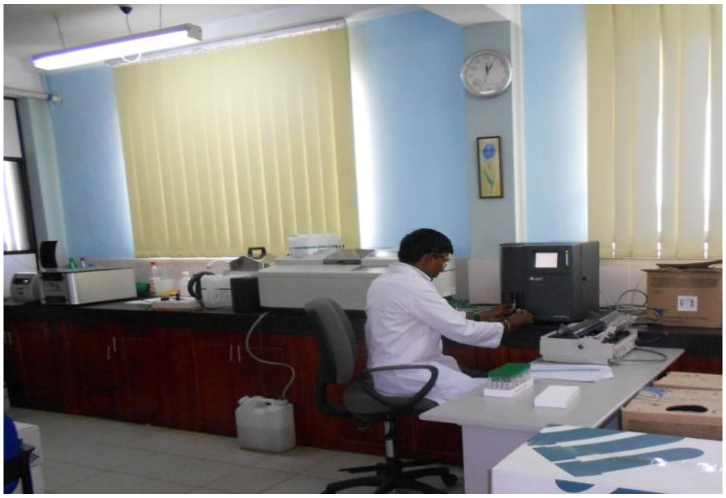
An outdoor garden was created with the help of well wishers. This allowed them to spend time outside the hospital walls, and enjoy the sunlight, fresh air and nature. All these changes made their stay a happy and homely one. As days passed we felt that they liked coming here more often than they used to do. Even the parents said that it was not easy to take them home after hospitalizations.

The outdoor garden

The Thalassaemia Diagnostic Laboratory

The Thalassaemia Diagnostic Laboratory which is functioning since 2003 is the first in the island to introduce the diagnosis of thalassaemia by HPLC method. The service of diagnosis of Thalassaemia and other Haemoglobinopathies is provided free of charge to the whole country. From its inception until 2009 this was done with funding from research grants from United Kingdom. We continued to provide services to the whole nation, as we were the only such laboratory in the country. Our efforts of getting state recognition were finally successful in 2009, when the Ministry of Health started funding our laboratory. With time three more diagnostic centers were established in the country however we continue to be the only lab which provides continuous screening to date and definitely the quickest to issue results. The people who present themselves to the lab are counseled and tested and the results are available within one week. If the patients cannot come back for results we post them the results and invite them for a counseling session. Extended family screening for identified carriers is done in all cases. First this laboratory was situated in North Colombo teaching hospital, professorial medical unit. When the unit moved to the new premises in 2011, we too shifted here as we were given a newly equipped furbished area in the second floor with much more comfortable waiting area for those who come for our services.

To date we function as the National reference laboratory.



Our achievements in management, treatment and care

Treatment and follow up of thalassaemic adults and adolescent children had to be carried out promptly and constantly. It was not an easy task to manage such a huge number of patients, as we had the second largest number of patients in the country, with a minimum staff of, one specialist and one medical officer. It was a great advantage for this unit as the Consultant of our unit remained attached to it since the beginning while specialists in other units in the country had to interchange every 4 years. This improved the outcome of management and care of patients.

A blood transfusion is required every 3-4 weeks for a patient with thalassaemia major and in all other units of the country a patient and a parent would spend at least 3-4 days in the hospital to get the work done. This has resulted in many patients defaulting treatment due to the pressure imposed on the other family members and loss of income to the parent concerned. We understood the necessity of a system that doesn't disturb their day to day living. Through friendly collaboration with the blood bank of the teaching hospital Ragama, we managed to get down blood for transfusions as early as possible during the day so that the patients who wished to go home could do so in the evening. Having developed and adopted this system, we saw that the patients were encouraged to come here on a regular basis on days that are convenient for them. They usually contact us through telephone and inform on their admissions for blood transfusions, and give blood for cross matching early as possible so that the blood units will be ready when they get admitted. This way we managed to shorten the hospital stay which saved lot of unnecessary time spent in ward. For the employed patients and those involved in studies we have managed to cut down the time spent in hospital to about 6 hours. The blood bank of Teaching Hospital Ragama gives an efficient continuous service with the requirement of blood products.

Initially most of the patients who came to us had extremely high iron levels. Some of them even over 10,000 units. There was no choice but to give them 24 hr IV DFO if we were to get their iron levels down, promptly. As now we had space we could offer them the services without much restrictions. In fact ours is the only unit in Sri Lanka where patients are given unlimited access for continuous IV DFO therapy. In most other units due to lack of space and organizational difficulties patients are given IV DFO only for a maximum of 7 days at a stretch.

Most patients do not need IV chelation and could be managed with sub cut DFO. The problem for them was the lack of availability of the pump. That hurdle too was overcome when we started attracting donors. Initially it was individual donations that kept the pumps coming in but since 2010 the Sri Lanka Navy has started to manufacture chelation pumps and now all patients who need pumps would get one free and without a delay.

The first unit to start oral iron chelation drug.

The oral iron chelation drug DFX (Deferasirox) was introduced to Sri Lanka in 2008, and it really made a big impact on treatment aspects as patients were tired of needle pricks. It was warmly welcomed by many and we are the first unit that started oral therapy with Deferasirox (Asunra). We bought the drug initially with the funds we had as it was not given out freely by the Health Ministry. It was given to 8 selected patients and monitored the outcome by serum ferritin levels as well as the complications. We found that the new drug not only made their day to day living easy but also showed a good improvement in lowering the iron level. We made it a point to inform the government authorities in writing, about the new improvements and the need to have it freely available. With these efforts we managed to get the attention of the government health authorities to provide the oral medications free of charge. As a result of our efforts now the majority of patients in Sri Lanka have access to DFX, free of charge of course, and in our unit 60 percents % of the patients are on it.

We get the services of a consultant endocrinologist attached to the main Ragama hospital to look into the endocrine issues of our patients. As most endocrine investigations are not done in the local hospital laboratory we mostly rely on high quality private sector labs for the reports. The costs for almost all of these investigations are met by the Foundation we have set up. In some situations where the hormonal preparations are not available in the hospital sector we buy it for our patients if they cannot do it themselves. Though the health care services are free in Sri Lanka it should not be understood that all teats and drugs are available all the time!

High serum ferritin levels

The main challenge we had to face at the beginning was patients with high serum ferritin levels. In the early days many were admitted with high ferritin levels as >10 000. When treating them we had to identify and overcome clinical as well as psycho-socio- economical problems they faced in life. Most of the adolescent children and their parents had poor knowledge about the treatment and outcome. This made them ignore the treatment regimes at home. The oral drug was not available in the early days when we had the highest number of patients with very high serum ferritin levels.

Serum Ferritin Levels	No. of patients on admission]	
<1000	5	4%
1000-2500	31	25%
2500-5000	34	27.4%
5000-10 000	32	25.8%
>10 000	23	18.5%

Table 1: Serum ferritin levels at admission to our unit

Most of the children refused desferioxamine sub-cutaneous infusions at home due to pain and irritations caused by needles. The problems differed from person to person and we had a struggle to identify individual shortcomings to overcome these problems. For some it was the pain and irritation of the S/C pump meanwhile some had psychological barriers to refuse medications as having daily infusions were a hindrance to their day to day living. After commencing treatment, we felt that just prescribing or advising parents and these teenage kids was not enough.

We found that giving them a reward for their achievements could make them involve actively in their own treatment process. So we made charts and books to document the times and amounts each one of them infused at home and made the parents sign to prove that they did so. This helped in many ways for the teenagers to lower their ferritin levels as they had a goal to be the best among others. We gave away presents and awards for those who showed progress.

Giving away presents for those who achieved low ferritin levels

We made sure that they used all the medications given. To check for compliance we collected the empty desferioxamine bottles at each visits to see how much they infused and we discussed their ferritin levels comparing with the old reports

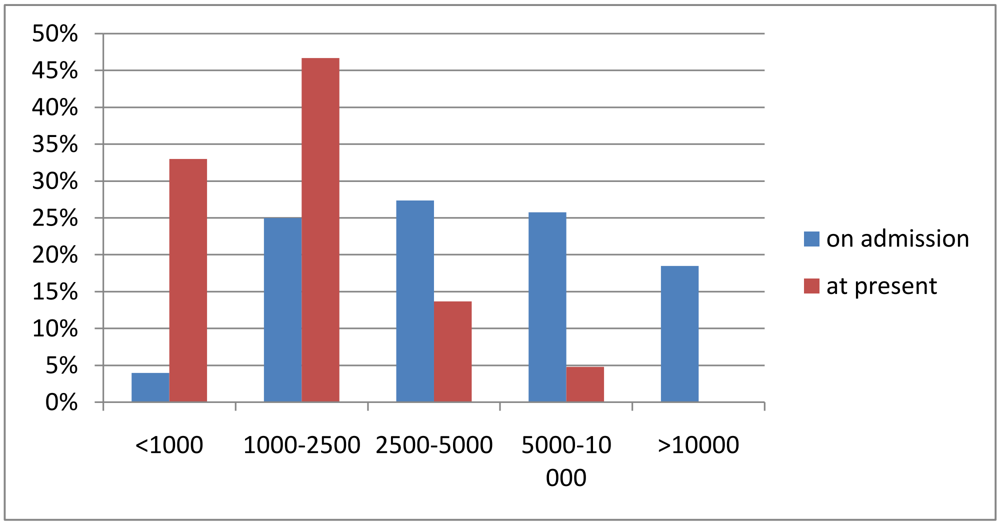
Still we found that some had to be reminded continuously. So we sent reminders in mail with information of complications of iron overload. For some daily telephone calls were essential to remind that they needed infusions. For those who defaulted clinics and treatment these reminders were effective to guide them back.

For those who had very high levels it was essential to hospitalize them to commence aggressive iron chelation therapy with intravenous infusions such as desferioxamine which should be infused for 24 hours continuously for 2-3 months. It was not an easy task to keep them in a ward for such a long time. For this, we had to change the ward set up as well as the attitude of the staff to create a homely environment for them in the thalassaemia unit. In our new premises, this was easily accomplished as we had built this place with such eventualities in mind.

As you can clearly see in the table below, iron levels of our patients decreased as time went by. By the year 2012 almost all had lesser ferritin levels than they had on admission.

Serum Ferritin	2009	2010	2011	2012
<1000	1%	8%	25%	33%
1000-2500	24%	38%	48%	46.7%
2500-5000	50%	42%	19%	13.7%
>5000	25%	12%	8%	4.8%

Table 2 : Iron Overload patients and variation of Serum Ferritin by year 2009 to 2012.



Graph 1: the serum Ferritin levels of our patients on admission and now.

Serum Ferritin Levels	No. of patients on admission]		No .of patients at present	
<1000	5	4%	41	33%
1000-2500	31	25%	61	46.7%
2500-5000	34	27.4%	17	13.7%
5000-10 000	32	25.8%	6	4.8%
>10 000	23	18.5%	0	0%

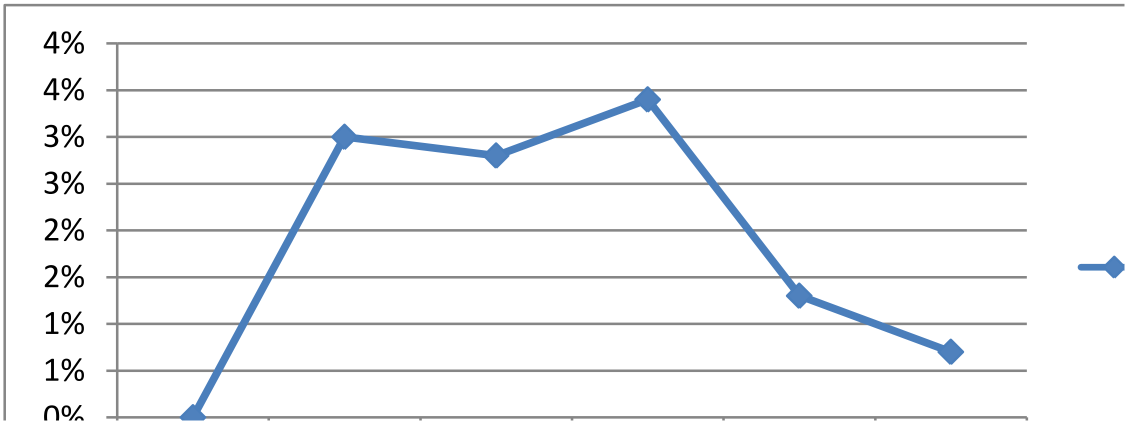
Table 3 compared values of serum Ferritin levels of our patients on admission and now

When the serum ferritin levels started lowering the complications and death rates too started to reduce drastically. Number of patients and number of deaths in our unit

Year	Total No. of patients	Total No. of deaths	Death rate
2006	15	0	0 %
2007	65	0	0%
2008	94	3	3%
2009	138	4	2.8%
2010	177	6	3.45%
2011	225	3	1.3%
2012	258	1	0.3%

Death Rate

Main reasons for deaths were the complications due to iron overload. When this was treated strictly and promptly, we managed to reduce the complications which lowered the death rate, even though the number of patients coming to us increased with years.



Graph 2 : Death rate of our unit from 2007 to 2012

How we overcame economic burdens

Treating a child with thalassaemia takes a lot of time, effort and support of a team that consists of medical experts, social supporters, counselors and their very own family members.

As Sri Lanka is a developing country and the majority of its people are poor it was unlikely that we could rely totally on the government for support for all our needs.. It was essential to establish support schemes in various aspects such as socio economic, emotional and psychological terms for patients and their families one step towards achieving this end was the establishment of the thalassaemia foundation for these patients.

Thalassaemia foundation for adult patients

Thalassaemia foundation for adult patients was established in 2007 with the parents of the children being the office bearers. It was an organization which supported self empowerment set up by us the staff members of the unit but where the key decisions of the foundation would be decided by the parents. Unlike is the case as is in other countries we do not have a strong parent and patient driven organization. Most decisions and progress of thalassaemia management is decided by the health authorities. The formation of the foundation was a step towards motivating the parents and patients in getting involved with policy. This was a wise approach as more the families got involved and felt important, the negative attitude toward their child's medical problem was would change. Within their foundation they had others who were going through the same pain and troubles as they did. This way we created a strong support system amongst them which used their own strength and abilities to fight for their rights. Through the years the foundation became strong with help and support of the families of our patients. It created a place to gather, converse and interact.

Scholarships were granted to patients who had a poor economic state. Most of our patients not only continued through high school but entered state universities and excelled in many fields of their interest because of the economic and psychological support provided to them through the foundation.

At present 10 of our patients have enrolled to state universities and 5 who are already graduated are working as government employees in their respective fields. 22 of them completed the high school education, with completion of GCE Advanced level and 91 have completed GCE ordinary level. This was a great achievement for the students themselves as well as to us, as earlier days many believed that thalassaemics couldn't live an ordinary life. Through proper management, care with guidance and counseling, we managed to fight against these social stigmas.

Oldest patient with Beta thalassaemia major, in Sri Lanka

Vocational training programs funded by well wishers, were organized in the premises with the help of the staff and parents of these kids. Many showed interest in the stitching and sawing program, which was carried out in the 2nd floor of our unit. Even parents joined in eagerly and made the kids learn something useful as well as earn some money through selling the products.

Their life events and social events were celebrated as one unit since the foundation grew stronger with more and more patients' and families' involvement. This gave them a chance to spend time together with the others who went through the same difficulties as them.

Sinhala and Hindu New Year's sports festival

"Forgetting their illness and hardships for awhile"

Kids competing at the New Year sports festival

Creating a solid base to enhance and improve their talents and skills

Entertaining the guests at the opening ceremony

Performing at the talent show

Though they are struggling with a disease that could weaken them every second, they were motivated to tap into their own talents. We gave them opportunities to showcase their creativity be it in writing, dancing or other fine arts. This made them understand their own value and perhaps took their minds off the disease at least for a moment.

We organized many talent shows and exhibitions that gave them a stage to present their skills.

The youngsters decorating the unit for a celebration.

Vegetable and fruit carvings of a talented young boy in our unit.

Kids performing at a celebration in our unit

Creations of our patients exhibited at the art show 2010

When we had to participate in national events such as World Thalassaemia day celebrations, these children got a chance to show case their talents to the wider society.

The dance team who performed at the 2013 National thalassaemia day

Annual trips were organized and it gave a chance for them to forget their hardships in life and enjoy moments of fun and pleasure. They felt that they are not fighting a battle on their own but there are others who had the same troubles and worries as they did. This allowed them to forget the center of their problems and blend together as one family. Every family was linked with each other because of the foundation and it gave them a ground to discuss and find solutions to their common problems. This way we achieved our main obstacle towards success as there was a strong support system for them within themselves.

Photos taken at annual trips

It must be stressed again that our unit was not one which existed in the national health structure. It was a dream that we dreamt and made sure that it became a reality. It was the very strong self belief that we all had that we must do something for a group of people forgotten largely by the health structure of the country and the rest of its people. Once we got it our outfit off the ground we have become the beneficiaries of many altruistic people. That helped us continue to support our patients. But as always is the case the needs are far greater that the help we get!

Creating awareness and Prevention

In 2008 the Ministry of Health of Sri Lanka recognized thalassaemia as an important public health problem. As it became aware that the management of patients was becoming a huge health burden it had wisely started to emphasize on prevention of new thalassaemia births. Four national centers were recognized to coordinate a nationwide prevention programme.. As the pioneers in establishing thalassaemia diagnosis in Sri Lanka, though we were outside the "thalassaemia belt" of Sri Lanka, we too were identified as a National centre for prevention. As the Sri Lankan penal code still considers termination of pregnancies for anything other than serious maternal health illegal, the options for prevention of thalassaemia has been limited to dissuasion of marriages of thalassaemia carriers. As unenviable a task that may be we had to start somewhere. The Ragama Prevention team was formed which consists of a medical officer the same one that runs the Thalassaemia care unit 5, nursing officers, 2 laboratory technicians and 2support employees.

Our task was to educate the public in a way that they would understand a complex genetic disease that is Thalassaemia and with the knowledge they themselves would initiate self directed screening voluntarily, and would take the message to their own villages and homes. We screened youth from Factories, Universities, schools and Government institutions.

Through public lectures and discussions we encouraged the public to test themselves for the disease as well as donate blood for the thalassaemia patients. The laboratory investigations were done free of charge by the thalassaemia diagnostic laboratory situated in our unit.

Since the awareness program penetrated the society in many levels, we had people coming to us from all over the country. Most of the young couples got themselves tested prior to marriage and many came for counseling when they wished to have children.

On Left : Our medical officer , addressing the public at a prevention programme. On right : a blood donation event conducted by our unit.

Let us summarize our achievements!

- This is the only unit in Sri Lanka dedicated for the management of adult Thalassaemic patients.
- This unit provides treatment to the second largest number of thalassaemia patients, in the country although it is situated in an area of lower thalassaemia prevalence.
- We have the highest percentage of patients with serum. Ferritin level <1000ng/dl among thalassaemia units in the country
- Our unit has the lowest death rate of thalassaemic patients in the country.
- We have our own laboratory with facilities for the diagnosis of Haemoglobinopathies and we are the only unit that provides facilities for genetic diagnosis.
- We are the only unit that provides optimum care of blood transfusion and Iron chelation on a system that is convenient for the patients where the patient spends the least time in hospital.
- We have drug supply system that provides the medications on a regular and continuous basis.
- We have created a strict follow up system that helps us identify Endocrine problems early and treat them accurately.
- We are actively involved in Thalassaemia screening and National Thalassaemia prevention program in Sri Lanka.
- Thalassaemia foundation for adults. We hold a strong support group with awareness of the living conditions of our patients and their families. We ease their psycho-social and economic needs by providing counseling, career guidance, vocational training facilities and scholarships.
- We conduct counseling programs on a regular basis for our patients to uplift their mental status and strength.
- We organize Annual trips for the patients and families to give them the opportunity to enjoy the country’s beauty as well as to get away from their daily hardships.
- We maintain a library within the unit for the patients to read and share when they are here for treatments.

Collection of Data from our Adolescent and adult thalassaemia unit.

Year	Number of Patients
2006	15
2007	65
2008	94
2009	138
2010	177
2011	225
2012	275
2013 May	286

Staff members of our unit

Care provided by under supervision of Prof. A.P. Premawardhena- MBBS, MD, MRCP, D.Phil (Oxon), FRCP (London) Consultant Physician, Head – Dept. of Medicine, Consultant In Charge of Thalassaemia Unit

Dr. D.P.S.Ishari Silva – Medical Officer in charge
Nursing officers
    Mrs. P.R.D.R. Piyatunga – Nursing officer in charge
    Mrs. M.A.N Nalani
    Mrs. R.M.M.D.T. Rajapakse
    Mrs. A.K.P. Manel
    Miss D.M.W. Dodamulla
    Miss M.P.V. Nilmini
Mr. Lakshman Perera – Technical Officer
Mr. Rexan Rodrigo – Development Assistant

Staff members	2006-2011	2011 onwards
Medical officer	1	1
Nursing officers	1	6
Technical Officer	1	1
Development Assistant	1	1
Supportive Staff	0	4

Diagnosis of the registered patients

Diagnosis	NO. of patients
βThal major	121
E βThalassaemia	51
Sβ Thalassaemia	8
Thalassaemia intermedia	57
Congenital Dyserythropoetic anaemia	3
Other Transfusions dependant anaemias	51