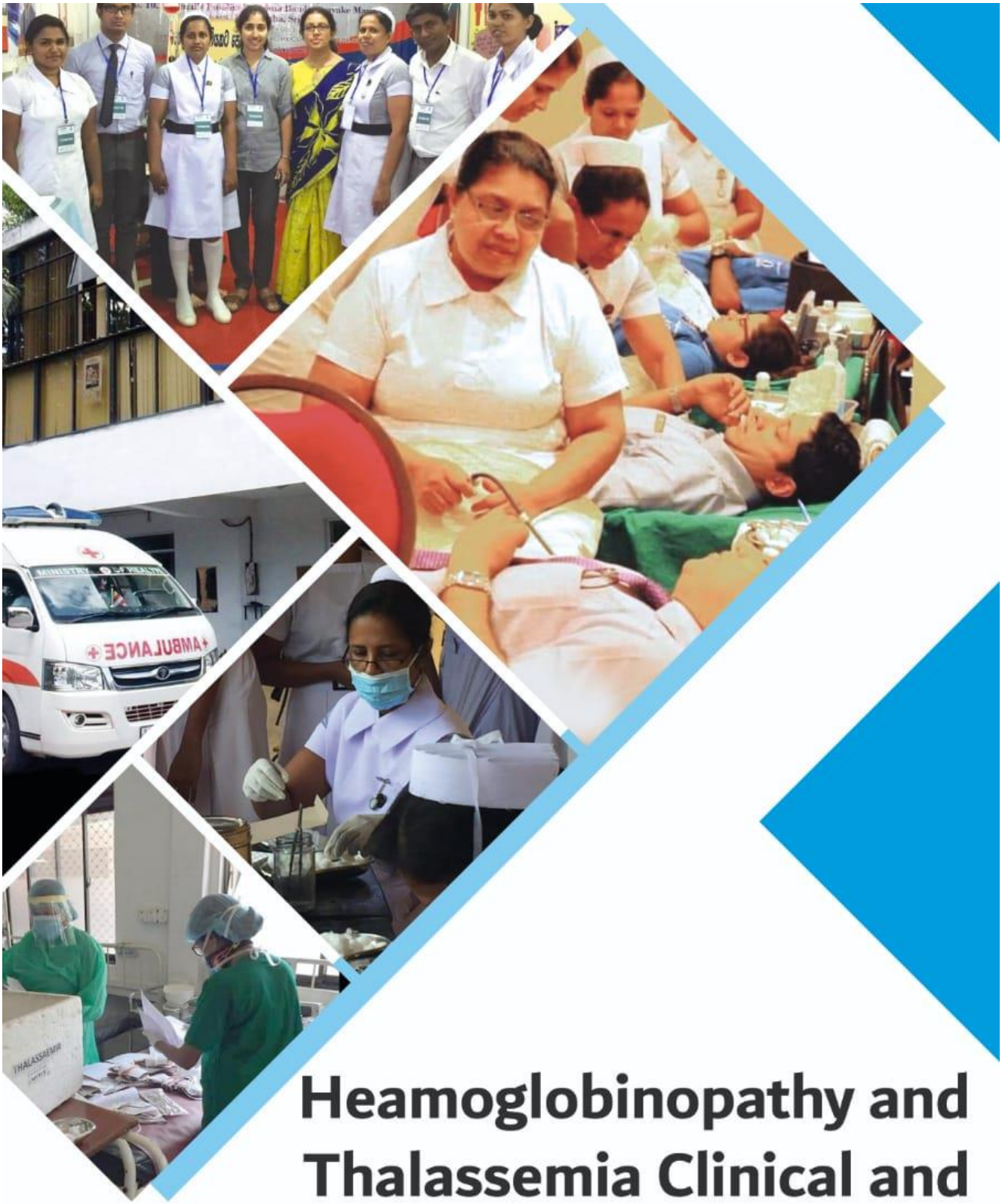


Heamoglobinopathy and Thalassemia Clinical and Diagnostic Services

North Colombo (Teaching) Hospital, Ragama
Faculty of Medicine, University Of Kelaniya

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

The Democratic Socialist Republic of Sri Lanka is an island situated in the northern Indian Ocean in South Asia. Sri Lanka is a country of 22 million people of four main ethnicities (Sinhalese, Tamils, Moors, Burghers) practicing several religions and speaking many languages, making it their home. It has a total land 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 to date around 2500 patients affected with the disease have been identified. The majority of them have beta thalassaemia major and Hb E beta thalassaemia.

The first thalassaemia patient in Sri Lanka was reported in 1952, but until the 1990s the management of thalassaemia was far from optimal. Blood transfusion availability was on a replacement basis and chelation was virtually non-existent. Arrival of the legendary the late Prof. Sir David Weatherall on the island and the collaboration he developed with Sri Lankan colleagues undoubtedly was the beginning of a new chapter of thalassaemia care in the country.

Studies done in 1997 and 2009 showed that the distribution of thalassaemia within the country was unequal. It is highly prevalent in North West province, North Central Province and Central Province. Nevertheless, thalassaemia patients are attending hospitals in more than 27 leading hospitals across the 25 districts.

The first ever dedicated thalassaemia centre in Sri Lanka was established in Kurunegala in 2002. 20 years later specialised thalassemia centres are still restricted to Anuradhapura,

Badualla, Chilaw, Ampara and to Ragama while thalassaemia patients continue to be managed in other districts in general paediatric or adult medical wards.

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 paediatricians 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 in the rest of the world are still not involved in the management of these patients who are transcending the paediatrics 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 quality of care for adolescent and adult thalassaemic patients in the country. In this essay we would attempt to narrate our story from the inception to the current status as of 2021.

Adolescent and Adult Thalassaemia Care Unit

The beginning

In 2002 August Dr Anuja Premawardhena then a senior 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 University 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 disappointing.

Being managed in a busy acute medical care unit, these adolescents were 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.

The 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 sceptical 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 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 next few years were 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 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.

After the renovation and refurbishment 2011

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 centre 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 centre on the second.

The auditorium ***the vocational training centre***

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 excited 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 patients cubicle 2011

The female patients cubicle 2011

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

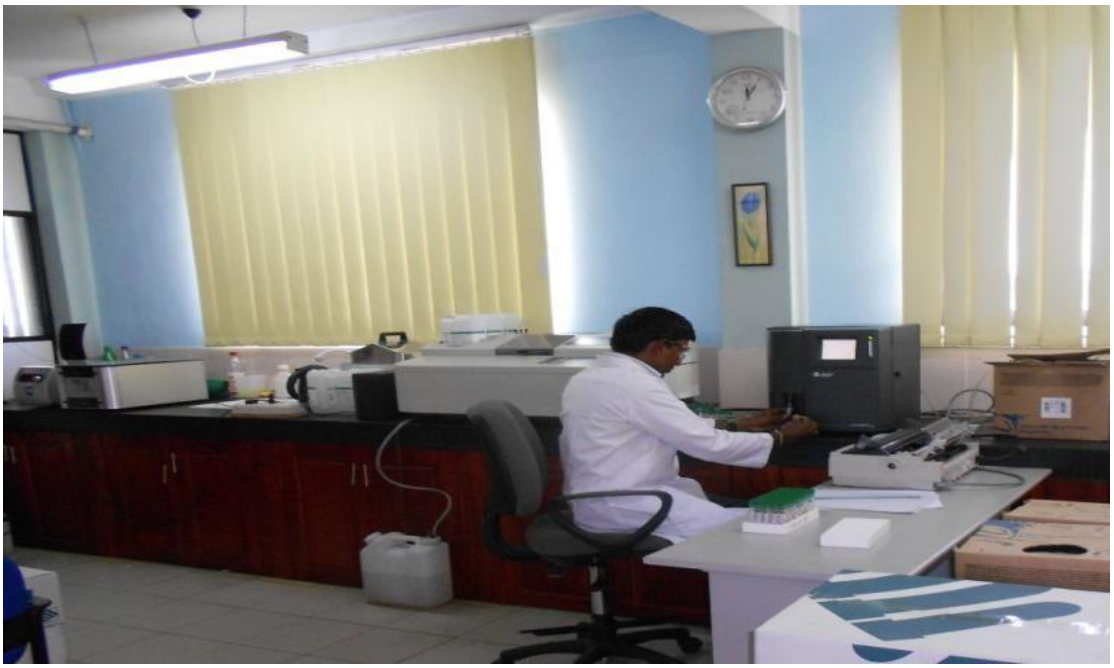
Indoor games such as carom, checkers and board games were kept in premises with easy access to them. They were encouraged to take part in these games to prevent boredom and loneliness.

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 several more diagnostic centres 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 counselled 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 counselling session. Extended family screening for identified carriers is done in all cases. First this laboratory was situated in North Colombo teaching hospital, University 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 a reference laboratory.



Thalassaemia Molecular Diagnostic Laboratory

In 2009 Molecular Investigation Laboratory for Thalassaemia began its operations as a speciality laboratory at the Molecular Medicine Unit of the Faculty of Medicine University of Kelaniya. This building complex was donated by the kind patronage of Prof. Sir David Weatherall and Colombo International Rotary Association.

The laboratory has developed into a research centre for haemoglobinopathy diagnosis, and is a speciality reference centre for alpha thalassaemia diagnosis. This is in addition to the service functions it contributes for the characterisation in the “difficult” cases of haemoglobinopathies.

.

The Thalassaemia Molecular Genetics Laboratory

Professor Sir David Weatherall & Prof Lal Chandrasena two key donors of the Molecular Medicine Unit

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.

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 percent of the patients are on it.

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- economic 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 regimens 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.

Table 1: Serum ferritin levels at admission to our unit

Serum Ferritin Levels	No. of patients on admission	
<1000	145	29%
1000-2500	119	24%
2500-5000	97	19%
5000-10 000	91	18%
>10 000	53	10%
Total	**505**	**100%**

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

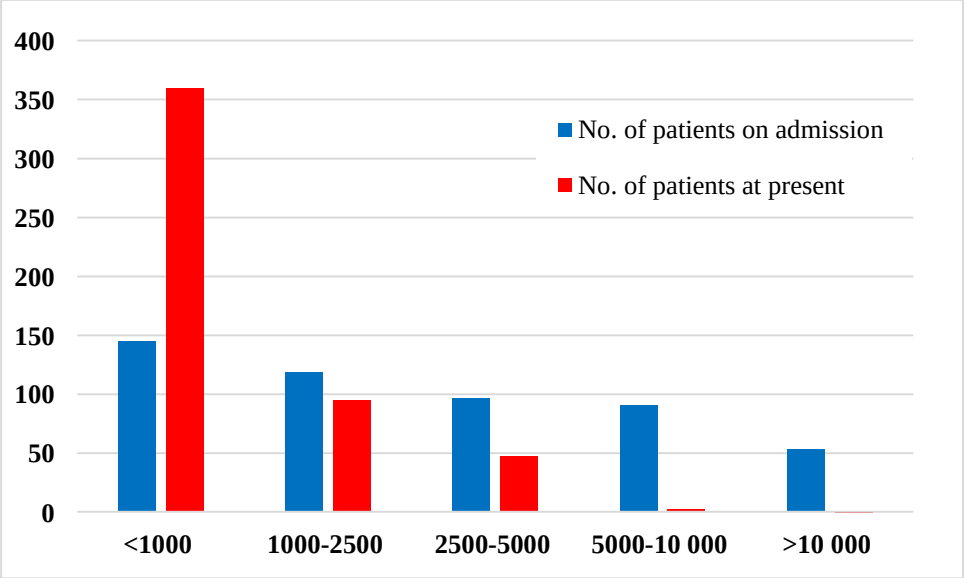
We made sure that they used all the medications given. To check for compliance, we collected the empty desferioxamine bottles at each visit to see how much they infused and we discussed their ferritin levels comparing with the old reports

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.

As you can clearly see in the table below, iron levels of our patients decreased as time went by. By the year 2020 almost all had lesser ferritin levels than they had on admission.

Table 2: Iron Overload patients and variation of Serum Ferritin by year 2009 to 2020.

Serum Ferritin	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020
<1000	1%	8%	25%	33%	36%	44%	40%	41%	52%	54%	63%	68%
1000-2500	24%	38%	48%	47%	52%	53%	52%	52%	38%	39%	37%	18%
2500-5000	50%	42%	19%	14%	10%	6%	8%	7%	8%	7%	0%	14%
>5000	25%	12%	8%	5%	2%	0%	0%	0%	2%	0%	0%	0%



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

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

Serum Ferritin Levels	No. of patients on admission		No. of patients at present	
<1000	145	28.7%	360	71.3%
1000-2500	119	23.6%	95	18.8%
2500-5000	97	19.2%	47	9.3%
5000-10 000	91	18.0%	2	0.4%
>10 000	53	10.5%	1	0.2%
Total	505	100%	505	100%

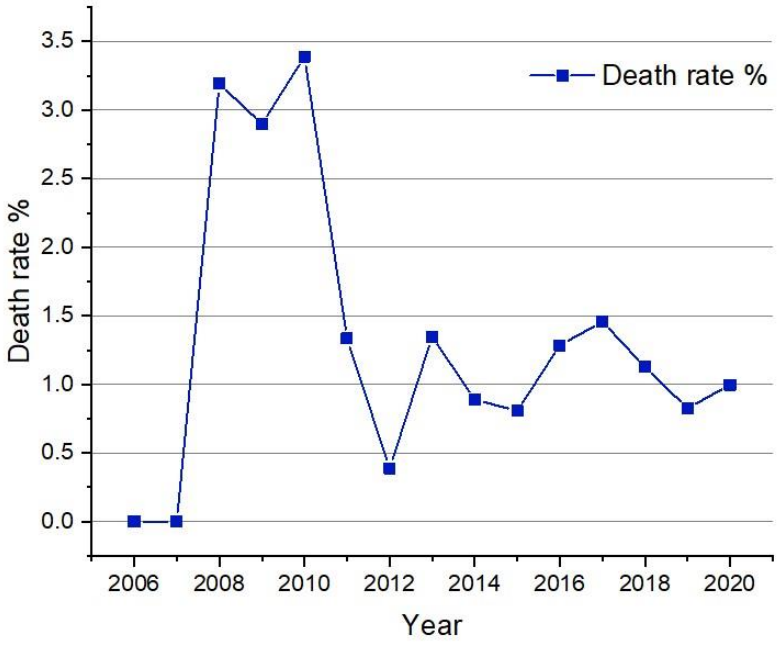
When the serum ferritin levels started lowering the complications and death rates too started to reduce drastically. Number of patients and number of deaths in our unit

Table 4. Total number of patients and deaths by year.

Year	Total number of patients	Total deaths	Death rate
2006	15	0	0.00%
2007	65	0	0.00%
2008	94	3	3.19%
2009	138	4	2.90%
2010	177	6	3.39%
2011	225	3	1.33%
2012	258	1	0.39%
2013	297	4	1.35%
2014	337	3	0.89%
2015	372	3	0.81%
2016	389	5	1.29%
2017	412	6	1.46%
2018	444	5	1.13%
2019	484	4	0.83%
2020	502	5	1.00%

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 2020

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, counsellors 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 counselling, we managed to fight against these social stigmas.

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.

Forgetting their illness and hardships for a while"

Sinhala and Hindu New Year's sports festival

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 talents 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 2014 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 centre 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 centres 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 have 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 2 support 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 counselling 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.

Public awareness campaigns at the MediCare Exhibition at BMICH

Thalassaemia Day celebration in 2019

A dance at the thalassaemia Day celebration event in 2019

A dance at the thalassaemia Day celebration event in 2019

Gift bags for patients on Thalassaemia day

The new expansions

Since 2011 over the last 10 years the thalassaemia unit has seen a steady growth in the number of patients. In parallel with this the resources too have expanded. At the present time (May 2021) the unit treats a total of 446 regular patients in addition to attending to the needs of a further 450 patients refereed or self-referrals from other centres in the country.

Tabel 5: Diagnosis of the registered patients

Diagnosis	No. of patients
Beta thalassemia major	179
E beta thalassaemia	76
S beta Thalassaemia	23
Thalassaemia intermedia	98
Others	70
Total	446

Expansion of the Thalassaemia unit

In 2011 the Unit functioned as a single floor for patients and one floor for laboratory services. At present, we have expanded to a 4-storied building. The top floor is a 150-seat auditorium. The 2nd floor has two laboratories. In addition to the thalassaemia diagnostic laboratory in 2020 a new "Red cell disorder" laboratory pioneered by Dr Shiromi Perera was opened up. This will concentrate on as yet neglected diseases like membranopathies and enzymopathies. The 1st floor houses the female ward and the clinic room and the ground floor is the male ward. Each ward has approximately 15 beds with space to expand

New Red Cell disorders diagnostic laboratory 2020

Opening of the Paediatric Thalassaemia Centre

The Paediatric Thalassaemia Centre of the Department of Paediatrics of the University of Kelaniya was opened in 2010 at the Colombo North Teaching Hospital, Ragama. This unit function as a tertiary referral centre for children with haemoglobinopathies and receive referrals from many parts of Sri Lanka. Currently, it cares for approximately 50 children with haemoglobinopathies and functions as a postgraduate teaching centre for trainees in General Paediatrics attached to the University Paediatrics Unit. In addition to the clinical management centre, the Department of Paediatrics has a Haematopoietic Stem Cell Laboratory which was established in 2018 with funding from the Medical Research Council and the Academy of Medical Sciences in the UK and National Research Council of Sri Lanka. This laboratory is equipped with the state-of-art instrument to perform tissue culture and haematopoietic stem cell research and provides training for graduate students doing in-vitro research on thalassaemia. A large number of in-vitro and clinical research studies conducted at the Paediatric Thalassaemia Centre have been published in high impact scientific journals. Currently, this centre has active collaborations with the University of Oxford and University of Cambridge in the UK and Mahidol University in Thailand.

Diagnostic services expanded

In 2016, diagnostic services were expanded with the inclusion of the Capillary electrophoresis. This has allowed the centre the take on the role of the centre for diagnosis for Gampaha District, a new defined role assigned by the Non-Communicable Diseases division of the Ministry of Health

Clinical Treatment expanded

With the participation of Dr Dulani Kottachchi, Consultant Endocrinologist and Senior Lecturer of the Faculty of Medicine, University of Kelaniya regular clinics are conducted for patients with endocrine issues.

Selected patients have access to liver iron estimation with R2 (Ferriscan) in a private sector hospital as part of a research project, and all others have liver and cardiac iron assessed using T2* technology MRI at the Lady Ridgeway Hospital.

The latest addition for clinical services is the dual services provided by Mr Chaminda Hettiarachchi psychological counsellor of the Ministry of Social services (Once a week) and Dr Aruni Hapangama, Consultant Psychiatrist and Senior Lecturer, who provides once a month in house clinics for patients with needs.

Higher education hub

Final year medical students spend a session at the thalassaemia unit as part of their medicine appointment from 2016 onwards. From 2015 post graduate trainees in Haematology spend 2 weeks at the centre. In addition to this the centre has at present attracted 7 post graduate research degree students (one M.Phil., and 6 Ph.D. students) from across the country. The academics in the centre have published over 150 articles, presented an equal number of scientific lectures over the last 10 years.

Post Graduates who completed degrees

Dr. Shiromi Perera

Degree awarded- PhD in Molecular Medicine, 2015

Short description about the postgraduate research:

Dr. Shiromi Perera holds a PhD form University of Kelaniya for the research titled “Molecular characterization of β thalassaemia intermedias in Sri Lanka” carried out between 2010-2014. Her postgraduate work was fund in part by National Research Council, Sri Lanka Research Grant No. NRC 09/13 and University Grant Commission, Sri Lanka Research Grant No. UGC/ICD/CRF/2009/29/1.

Mr. Rexon Rodrigo

Degree awarded: MPhil in Molecular Biology, 2016

Short description about the postgraduate research:

Mr. Rexan obtained an M.Phil. degree in Molecular Biology from the University of Kelaniya for the research titled " Molecular diagnosis of common alpha plus thalassaemia deletions and alpha triplications in Sri Lanka" between 2013- 2016.

Dr. L.G.T. Dharshana

Degree awarded: PhD in Molecular Medicine and Clinical Haematology, 2020

Dr. Thamal Darshana is a senior lecturer in Medical Laboratory Sciences and a researcher at Faculty of Allied Health Sciences, University of Sri Jayewardenepura. His research interests span in the areas of molecular biology and haematology. He is involved in researches about haemoglobinopathies particularly sickle cell disease and its manifestation.

Short description about the postgraduate research:

Dr. Darshana holds a Ph.D. form University of Kelaniya for the research titled "The genetic origin(s) and the distribution of the sickle cell gene and the clinical description of sickle cell disease in Sri Lanka" carried out between 2016-2020. His postgraduate work was fund by National Research Council – Sri Lanka under the grant number NRC 16-001.

Current Post Graduate Students

Mrs. N. Y. Yasara

PhD student, Faculty of Medicine, University of Kelaniya

Email: yasara8@gmail.com

Research Project: Foetal haemoglobin induction as a treatment for β-thalassemia

Supervisors: Prof. Sachith Mettananda & Prof. Anuja Premawardhena

Mrs N. Yasara has completed her undergraduate degree in medical sciences, MSc in Biochemistry and Molecular Biology and currently reading her PhD degree in Molecular Medicine. She is working on several research projects involving thalassaemia, and her main focus is to identify the ability to utilize foetal haemoglobin induction as a novel treatment modality for beta-thalassaemia. She has published several international publications on beta-thalassemia and won a senate honours award in 2020 for conducting high quality research.

Mrs. Ruwindi Lakmina Silva

PhD Student, Faculty of Medicine, University of Kelaniya

Email: silvaruwindi@gmail.com

Research Project: Comprehensive analysis of uncharacterized haemolytic anaemia and methemoglobinemia in Sri Lanka

Supervisors: Prof. Anuja Premawardhena & Dr. Shiromi Perera

Membranopathies and enzymopathies are groups of inherited haemolytic anaemias (IHAs) caused due to red cell membrane defects and red cell enzyme deficiencies. In Sri Lanka, contribution of these disorders to the burden of IHAs in the community is not well identified and there is no proper diagnostic protocol available for their accurate diagnosis. As a result, most of the cases remain undiagnosed and are often treated based on symptoms. Therefore, our research aims to develop screening methods and to identify the underlying cause for these genetic disorders thereby enabling to establish a reference laboratory

Miss. A.A.D.S Amarasingha

PhD Student, Faculty of Medicine, University of Kelaniya

Email: dinusha.s.amarasingha@gmail.com

Research Project: Comprehensive biochemical and molecular analysis of uncharacterized anaemia in the community in Sri Lanka

Supervisors: Prof. Anuja Premawardhena & Dr. Shiromi Perera

Anaemia is defined as the reduction in the haemoglobin concentration below normal levels. According to the WHO, the worldwide prevalence of anaemia is 25% of the world's population. It affects not only human health but also social and economic development of the community in both developed and developing countries. The underline causes for anaemia include iron deficiency anaemia, malaria, parasitic infection, nutritional deficiencies, enzymopathies, membranopathies and haemoglobinopathies. Among these factors, the main contributing factor for anaemia is iron deficiency. The relative contribution of these different types of anaemias to the disease burden of the community varies in different countries. Therefore, we cannot directly apply global statistics to any country without studying the local dynamics.

Mrs. Shyamali Thilakarathne

PhD Student, Faculty of Medicine, University of Kelaniya

Email: shyamali5thilakarathne@gmail.com

Research Project: Milder forms of beta-thalassaemia; unresolved clinical and laboratory issues of the heterozygous state of beta-thalassaemia

Principal Investigator: Ms. Shyamali Thilakarathne
Supervisors: Prof. Anuja Premawardhen & Prof. H.M.T.U. Herath

Though considered a harmless entity, many clinical and laboratory issues of the heterozygous state of beta thalassaemia (βTT) remains unresolved. The diagnosis is based on Hb A2 values and the values used are not necessarily applicable across all nationalities. Secondly, diagnosis of βTT may be affected by iron deficiency as it is believed by some researchers that iron deficiency reduces Hb A2 level. Further, community-based studies have identified a high prevalence of folate deficiency in Sri Lanka. It may very well be that the mild haemolytic anaemia that occurs in βTT makes them more vulnerable for folate deficiency. Pregnancy outcomes and complications in βTT are again a very ambiguous area with many clinicians transfusing βTT in pregnancy perhaps excessively. Therefore, our research aims to determine a country specific cut-off value for Hb A2, to determine the effect of co- existing iron deficiency on Hb A2 level, to determine the need for folic acid supplementation and to determine complications and outcomes in pregnancy.

Research Publications in the haemoglobinopathy field

1. Olivieri NF, De Silva S, **Premawardena A**, Sharma S, Viens AM, Taylor CM, Brittenham GM and Weatherall DJ. Iron overload and iron-chelating therapy in haemoglobin E-beta thalassemia. J Pediatr Hematol Oncol. 2000; 22(6):593-7
2. De Silva S, Fisher CA, **Premawardhena A**, Lamabadusuriya SP, Peto TE, Perera G, Old JM, Clegg JB, Olivieri NF, Weatherall DJ. Thalassaemia in Sri Lanka: implications for the future health burden of Asian populations. Sri Lanka Thalassaemia Study Group. Lancet. 2000; 355(9206):786-91.
3. **Premawardhena A**, Fisher CA, Fathiu F, de Silva S, Perera W, Peto TE, Olivieri NF and Weatherall DJ. Genetic determinants of jaundice and gallstones in haemoglobin E beta thalassaemia. Lancet. 2001; 357(9272):1945-6.
4. **Premawardhena A**, Fisher CA, Liu YT, Verma IC, de Silva S, Arambepola M, Clegg JB, Weatherall DJ. The global distribution of length polymorphisms of the promoters of the

glucuronosyltransferase 1 gene (UGT1A1): hematologic and evolutionary implications. Blood Cells Mol Dis. 2003; 31(1):98-101.

5. Fisher CA, **Premawardhena A**, de Silva S, Perera G, Rajapaksa S, Olivieri NA, Old JM, Weatherall DJ; The Sri Lanka Thalassaemia Study Group. The molecular basis for the thalassaemias in Sri Lanka. Br J Haematol. 2003; 121(4):662-71.
6. **Premawardhena A**, De Silva S, Arambepola M, Olivieri N, Merson L, Muraco J, Allen A, Fisher C, Peto T, Vichinsky E and Weatherall D. Thalassemia in Sri Lanka: a progress report. Hum Mol Genet. 2004; 1(2): R203-6.
7. **Premawardhena A**, De Silver S, Arambepola M, Olivieri NF, Vichinsky EP, Merson L, Muraco G, Allen A, Fisher C, Peto T, Weatherall DJ. Hemoglobin E-beta-thalassemia: Progress report from the International Study Group. Ann N Y Acad Sci. 2005; 1054:33-9.
8. **Premawardhena A**, Fisher CA, Olivieri NF, de Silva S, Arambepola M, Perera W, O'Donnell A, Peto TE, Viprakasit V, Merson L, Muraca G and Weatherall DJ. Haemoglobin E beta thalassaemia in Sri Lanka. Lancet. 2005; 366(9495):1467-70.
9. **Premawardhena A,** Fisher CA, Olivieri NF, de Silva S, Sloane-Stanley J, Wood WG and Weatherall DJ. A novel molecular basis for beta thalassemia intermedia poses new questions about its pathophysiology. Blood. 2005; 106(9):3251-5.
10. O'Donnell A, **Premawardhena A**, Arambepola M, Allen SJ, Peto TE, Fisher CA, Rees DC, Olivieri NF and Weatherall DJ. Age-related changes in adaptation to severe anaemia in childhood in developing countries. Proc Natl Acad Sci 2007; 104(22):9440-4.
11. Olivieri NF, Muraca GM, O'Donnell A, **Premawardhena A**, Fisher C and Weatherall DJ. Studies in haemoglobin E beta-thalassaemia. Br J Haematol. 2008; 141(3):388-97.
12. **Premawardhena A**, Arambepola M, Katugaha N and Weatherall DJ. Is the beta thalassaemia trait of clinical importance? Br J Haematol.2008; 141(3):407-10.
13. Lok CY, Merryweather-Clarke AT, Viprakasit V, Chinthammitr Y, Srichairatanakool S, Limwongse C, Oleesky D, Robins AJ, Hudson J, Wai P, **Premawardhena A**, de Silva HJ, Dassanayake A, McKeown C, Jackson M, Gama R, Khan N, Newman W, Banait G, Chilton A, Wilson-Morkeh I, Weatherall DJ and Robson KJ. Iron overload in the Asian community. Blood. 2009; 114(1):20-5.
14. O'Donnell A, **Premawardhena A**, Arambepola M, Samaranayake R, Allen SJ, Peto TE, Fisher CA, Cook J, Corran PH, Olivieri NF and Weatherall DJ. Interaction of malaria with a common form of severe thalassemia in an Asian population. Proc Natl Acad Sci. 2009; 106(44):18716-21.

15. Allen A, Fisher C, **Premawardhena A**, Peto T, Allen S, Arambepola M, Thayalsutha V, Olivieri N and Weatherall D. Adaptation to anaemia in Haemoglobin E-ß thalassemia. Blood. 2010; 116(24):5368-70.
16. Olivieri NF, Thayalsuthan V, O'Donnell A, **Premawardhena A**, Rigobon C, Muraca G, Fisher C and Weatherall DJ. Emerging insights in the management of hemoglobin E beta thalassemia. Ann N Y Acad Sci. 2010; 1202:155-7.
17. Sankaran VG, Xu J, Byron R, Greisman HA, Fisher C, Weatherall DJ, Sabath DE, Groudine M, Orkin SH, **Premawardhena A** and Bender MA. A functional element necessary for fetal hemoglobin silencing. N Engl J Med. 2011; 365(9):807-14.
18. Allen A, Fisher C, **Premawardhena A,** Bandara D, Perera A, Allen S, St Pierre T, Olivieri N and Weatherall DJ. Methemoglobinemia and ascorbate deficiency in hemoglobin E β thalassemia: metabolic and clinical implications. Blood. 2012 ;120(15):2939-44.
19. Nilanga N & **Premawardhena A**. The Thal-index with the BTT prediction.exe to discriminate β-thalassaemia traits from other microcytic anaemias. Thalassaemia Reports. 2012; l2(1)
20. Suresh S, Fisher C, Ayyub H, **Premawardhena A**, Allen A, Perera A, Bandara D, Olivieri N, Weatherall D. Alpha thalassaemia and extended alpha globin genes in Sri Lanka. Blood Cells Mol Dis. 2013; 50(2):93-8.
21. Cheng-Tao Yang, Anna French, Pollyanna Agnes Goh, Alistair Pagnamenta, **Sachith Mettananda**, Jenny Taylor, Sam Knight, Amit Nathwani, David J. Roberts, Suzanne M. Watt and Lee Carpenter. Human induced pluripotent stem cell derived erythroblasts can undergo definitive erythropoiesis and co-express gamma and beta globins. British Journal of Haematology 2014; 166 (3): 435-48.
22. Nishad AA, de Silva IS, Perera HL, **Pathmeswaran A**, Kastutiratne KT, Premawardhena AP. Role of red cell distribution width in screening for Hb E trait in population screening for haemoglobin disorders. J Pediatr Hematol Oncol. 2014; 36(8): e490-2.
23. **Mettananda S**, Gibbons R, Higgs D. α-Globin as a molecular target in the treatment of β-thalassemia. Blood 2015; 125(24): 3694-701.
24. **Perera PS**, Silva I, Hapugoda M, Wickramarathne MN, Wijesiriwardena I, Efremov DG, Fisher CA, Weatherall DJ and **Premawardhena A**. Rare hemoglobin variants: Hb G-Szuhu (HBB: c.243C>G), Hb G-Coushatta (HBB: c.68A>C) and Hb Mizuho (HBB: c.206T>C) in Sri Lankan families. Haemoglobin. 2015; 39(1):62-5.
25. Jones E, Pasricha SR, Allen A, Evans P, Fisher CA, Wray K, **Premawardhena A**, Bandara D, Perera A, Webster C, Sturges P, Olivieri NF, St Pierre T, Armitage AE, Porter JB,

Weatherall DJ and Drakesmith H. Hepcidin is suppressed by erythropoiesis in haemoglobin E β-thalassemia and β-thalassemia trait. Blood. 2015; 125(5):873-80.

26. **Mettananda S**, Gibbons R, Higgs D. Understanding α-globin gene regulation and implications for the treatment of β-thalassemia. Annals of the New York Academy of Sciences 2016; 1368(1): 16-24.
27. **Mettananda S**, Fisher CA, Jackie A. Sloane-Stanley, Taylor S, Udo Oppermann, Richard J. Gibbons, and Douglas R. Higgs. Selective silencing of a-globin by the histone demethylase inhibitor IOX1: A potentially new pathway for treatment of β-thalassemia. Haematologica 2017; 102: e80-e84.
28. **Mettananda S**, Fisher CA, Hay D, Badat M, Quek L, Clark K, Hublitz P, Downes D, Kerry J, Gosden M, Telenius J, Jackie A. Sloane-Stanley, Faustino P, Coelho A, Doondeea J, Usukhbayar B, Sopp P, Jacqueline A. Sharpe, Jim R. Hughes, Vyas P, Gibbons RJ & Higgs DR. Editing an α-globin enhancer in primary human hematopoietic stem cells as a treatment for β-thalassemia. Nature communications 2017; 8: 424.
29. **Mettananda S**, de Silva DGH. Anaemia in children: are we using the correct prevention strategies? Ceylon Medical Journal 2017; 62: 73-76.
30. **Mettananda S.** Thalassaemia: In a quest towards an ultimate cure. Sri Lanka Journal of Child Health 2017; 46(3): 203-10.
31. **Mettananda S,** de Silva H. Periodic deworming practice in Sri Lanka: Is it based on evidence, misconceptions or commercialism? Sri Lanka Journal of Child Health 2017; 46(4): 307-311.
32. **Mettananda S,** de Silva DGH. Re: Anaemia and iron deficiency in pregnant women attending an antenatal clinic in a Teaching Hospital in Southern Sri Lanka. Ceylon Medical Journal 2017; 62: 255.
33. Wray K, Allen A, Evans E, Fisher C, **Premawardhena A, Perera L, Rodrigo** Goonathilaka G, Ramees L, Webster C, Armitage AE, Prentice AM, Weatherall DJ, Drakesmith H, Pasricha SR. Hepcidin detects iron deficiency in Sri Lankan adolescents with a high burden of hemoglobinopathy: A diagnostic test accuracy study. Am J Hematol. 2017; 92(2):196-203.
34. **Premawardhena A**, Allen A, Piel F, Fisher C, Perera L, Rodrigo R, Goonathilaka G, Ramees L, Peto T, Olivieri N and Weatherall D. The evolutionary and clinical implications of the uneven distribution of the frequency of the inherited haemoglobin variants over short geographical distances. Br J Haematol. 2017;176(3):475-484.

35. Allen A, Allen S, **Rodrigo R, Perera L,** Shao W, Li C, Wang D, Olivieri N, Weatherall DJ, **Premawardhena A**. Iron status and anaemia in Sri Lankan secondary school children: A cross-sectional survey. PLoS ONE 12(11): e0188110. https://doi.org/10.1371/journal.pone.0188110
36. Premathilaka LHRA, Lakmini MS, Dharshana LGT, Nawaratne SB, **Mettananda S**, De Silva ST, **Premawardhena AP**. Stroke in sickle cell beta thalassemia-a case report highlighting pitfalls in management in a low prevalence country. Sri Lanka Journal of Medicine 2017; 26(2):55–57.
37. **Mettananda S**, Higgs DR. Molecular basis and genetic modifiers of thalassemia. Hematology/Oncology Clinics of North America 2018; 32 (2): 177–191.
38. **Mettananda S,** Clark K, Fisher CA, Jackie A. Sloane-Stanley, Gibbons RJ, Higgs DR. Phenotypic and molecular characterization of a serum-free miniature erythroid differentiation system suitable for high throughput screening and single cell assays. Experimental Hematology 2018; 60: 10–20.
39. **Mettananda S,** Suranjan M, Fernando R, Dias T, Mettananda C**, Rodrigo R**, **Perera L**, Gibbons RJ, **Premawardhena A**, Higgs DR. Anaemia among females in child-bearing age: Relative contributions, effects and interactions of α- and β-thalassaemia. PLoS One 2018; 13(11): e0206928.
40. **Mettananda S**. Management of thalassaemia. Sri Lanka Journal of Child Health 2018; 47(2): 159-165.
41. Suriapperuma T, Peiris R, Mettananda C, **Premawardhena A**, **Mettananda S**. Body iron status of children and adolescents with transfusion dependent β-thalassaemia: Trends of serum ferritin and associations of optimal body iron control. BMC Research Notes 2018; 11: 547.
42. **Mettananda S**. Thalassaemia: Current research may provide a cure for it in the future. Sri Lanka Journal of Child Health 2018; 47(4): 372.
43. **Rodrigo R**, Allen A, Manampreri A, Perera L, Fisher CA, Allen S and **Premawardhena A**. Haemoglobin variants, iron status and anaemia in Sri Lankan adolescents with low red cell indices: A cross sectional survey. Blood Cells Mol Dis. 2018; 71:11-15.
44. **Premawardhena A and Perera PS**. Anaemia in Sri Lanka: the missing pieces. Ceylon Med. J. 2018; 63(3):105-107.
45. **Mettananda S**, Pathiraja H, Peiris R, Wickramarathne N, Bandara D, de Silva U, Mettananda C, **Premawardhena A**. Blood transfusion therapy for β-thalassaemia major

and haemoglobin E β-thalassaemia: Adequacy, trends and determinants in Sri Lanka. Pediatric Blood and Cancer 2019; 66: e27643.

46. Allen A, **Perera S**, **Perera L, Rodrigo R, Mettananda S**, Matope A, **Silva I**, **Hameed N,** Fisher CA, Olivieri N, Weatherall D, Allen S, **Premawardhena A**. A "one-stop" screening protocol for haemoglobinopathy traits and iron deficiency in Sri Lanka. Frontiers in Molecular Biosciences 2019; 6: 66.
47. **Mettananda S**, Pathiraja H, Peiris R, Bandara D, de Silva U, Mettananda C, Premawardhena A. Health related quality of life among children with transfusion dependent β-thalassaemia major and haemoglobin E β-thalassaemia in Sri Lanka: a case control study. Health and Quality of Life Outcomes 2019; 17:137.
48. **Mettananda S**, **Yasara N,** Fisher CA, Taylor S, Gibbon RJ, Higgs DR. Synergistic silencing of a-globin and induction of g-globin by histone deacetylase inhibitor, vorinostat as a potential therapy for b-thalassaemia. Scientific Reports 2019; 9:11649.
49. Patel P, Beamish P, da Silva TL, Kaushalya D, **Premawardhena A**, Williams S, et a Examining depression and quality of life in patients with thalassemia in Sri Lanka. Int J Non Commun Dis 2019; 4:27 33.
50. Allen A, **Premawardhena A**, Allen S, **Rodrigo R**, Manamperi A, **Perera L**, Wray K, Armitage A, Fisher C, Drakesmith A, Robson K, Weatherall D. The p.H63D allele of the HFE gene protects against low iron stores in Sri Lanka. Blood Cells Mol Dis. 2019 May; 76:72-77
51. **Premawardhena A**, Ranawaka U, Pilapitiya T, Weerasinghe G, Hapangama A, Hettiarachchi S, Pathmeswaran A, Salvin K, Silva I, Hameed N, Weatherall M, Olivieri N, Weatherall D. Headache: an important symptom possibly linked to white matter lesions in thalassaemia. Br J Haematol. 2019 May;185(3):541-548.
52. **Premawardhena A**, Fernando R, Kumarage S, Nishad N, Goonatilleke D, Silva I, Mettananda S. Place for elective cholecystectomy for patients with severe thalassaemia: a retrospective case control study. BMC Res Notes. 2019 Apr 29;12(1):245.
53. **Perera S**, Allen A, Silva I, Hapugoda M, Wickramarathne MN, Wijesiriwardena I, Allen S, Rees D, Efremov DG, Fisher CA, Weatherall DJ, **Premawardhena A**. Genotype phenotype association analysis identifies the role of α globin genes in modulating disease severity of β thalassaemia intermedia in Sri Lanka. Sci Rep. 2019 Jul 12;9(1):10116.
54. **Premawardhana AP**, Mudiyanse R, De Silva ST, Jiffry N, Nelumdeniya U, de Silva U, Lamabadusuriya SP, Pushpakumara K, Dissanayaka R, Jansz M, Rifaya I, Navarathne U, Thirukumaran V, Arambepola M, Dayanada Bandara W, Vaidyanatha U, Mendis D,

Weerasekara K, De Silva N, Shantha Kumara DK, Amarasena SD, Hemantha KK, Refai MACM, Silva I, Hameed N, Rajiyah F, Mettananda S, Allen A, Weatherall DJ, Oliveri NF. A nationwide survey of hospital-based thalassemia patients and standards of care and a preliminary assessment of the national prevention program in Sri Lanka. PLoS One. 2019 Aug 16;14(8)

55. **Yasara N,** Wickramarathne N, Mettananda C, Manamperi A, **Premawardhena A, Mettananda S**. Efficacy and safety of oral hydroxyurea in transfusion dependent b-thalassaemia: a protocol for randomised double-blind controlled clinical trial. BMJ Open 2020; 10: e041958.
56. **Mettananda S**, Williams S. Clinical and laboratory evaluation of childhood anaemia. Sri Lanka Journal of Child Health 2020; 49(1):64-70.
57. **Mettananda S**. Improving the standards of care for children with thalassaemia in Sri Lanka. Sri Lanka Journal of Child Health 2020; 49(1):94.
58. **Mettananda S**. Recent developments in the treatment of transfusion dependent thalassaemia. Ceylon Medical Journal 2020; 65: 35-38.
59. **Perera S,** Bonsall D, Niriella MA, Allen A, Peries AC, Nelumdeniya UB, Dissanayake R, Silva I, de Cesare M, Klenerman P, Weatherall DJ, Roberts DJ, **Premawardhena AP**. Transfusion-transmitted hepatitis C: A cluster of cases in transfusion-dependent thalassaemia patients in Sri Lanka. Transfusion Med. 2020;1–7. https://doi.org/10.1111/tme. 12660
60. **Mettananda S**, Paranamana S, Fernando R, Suranjan M, Rodrigo R, Perera L, Vipulaguna T, Fernando P, Fernando M, Dayanath BKTP, Costa Y, **Premawardhena A**. Microcytic anemia in children: parallel screening for iron deficiency and thalassemia provides a useful opportunity for thalassemia prevention in low- and middle-income countries. Pediatr Hematol Oncol. 2020 May;37(4):326-336.
61. **Padeniya P**, Siriwardana S, Ediriweera D, Samarasinghe N, Silva S, Silva I, Ahamed N, Niriella M, **Premawardhena A**. Comparison of liver MRI R2(FerriScan®) VS liver MRI T2* as a measure of body iron load in a cohort of beta thalassaemia major patients. Orphanet J Rare Dis. 2020 Jan 22;15(1):26.
62. Reed-Embleton H, Arambepola S, Dixon S, Maldonado BN, **Premawardhena A**, Arambepola M, Khan JAM, Allen S. A cost-of-illness analysis of β-Thalassaemia major in children in Sri Lanka - experience from a tertiary level teaching hospital. BMC Pediatr. 2020 May 27;20(1):257.

63. **Premawardhena AP**, De Silva ST, Goonatilleke MDDC, Ediriweera DS, **Mettananda S**, Rodrigo BKRP, Allen A, Weatherall DJ. Marriage patterns in Sri Lanka and the prevalence of parental consanguinity in patients with β-thalassaemia: a cross-sectional descriptive analysis. J Biosoc Sci. 2020 Jul;52(4):573-584.
64. **Mettananda S**, Peiris R, Pathiraja H, Chandradasa M, Bandara D, de Silva U, Mettananda C, **Premawardhena A**. Psychological morbidity among children with transfusion dependent β-thalassaemia and their parents in Sri Lanka. PLoS One. 2020 Feb 11;15(2)
65. **Darshana T**, Bandara D, Nawarathne U, de Silva U, Costa Y, Pushpakumara K, Pathirage S, Basnayake S, Epa C, Dilrukshi P, Wijayawardena M, Anthony AA, Rodrigo R, Manamperi A, Smith F, Allen A, Menzel S, Rees D, **Premawardhena A**. Sickle cell disease in Sri Lanka: clinical and molecular basis and the unanswered questions about disease severity. Orphanet J Rare Dis. 2020 Jul 6;15(1):177.
66. Yasara N, Wickramarathne N, Mettananda C, Manamperi A, **Premawardhena A, Mettananda S**. Efficacy and safety of oral hydroxyurea in transfusion-dependent βthalassaemia: a protocol for randomised double-blind controlled clinical trial. BMJ Open. 2020 Oct 27;10(10)
67. Arunath V, Hoole T, Rathnasri A, Muthukumarana O, Kumarasiri I, Liyanage N, Costa Y, **Mettananda S**. A child with Imerslund-Gräsbeck syndrome concealed by co-existing α-thalassaemia presenting with subacute combined degeneration of the spinal cord: a case report. BMC Pediatrics 2021; 21: 41.
68. Allen A, **Perera S**, **Mettananda S**, **Rodrigo R, Perera L, Darshana T**, Moggach F, Anthony Jackson-Crawford, Heirene L, Fisher CA, Olivieri N, Rees D, **Premawardhena A,** Allen S. Oxidative status in the β-thalassemia syndromes in Sri Lanka; a cross-sectional survey. Free Radical Biology & Medicine 2021; (in press)
69. **Mettananda S.** Screening of children with anaemia for iron deficiency and thalassemia trait provides an opportunity for thalassemia prevention in Sri Lanka. Sri Lanka Journal of Child Health 2021; 50(2):
70. Hoole TJ, Visvalingam A, de Silva MHAD, Muthukumarana OGW, Kumarasiri IM, Rathnasiri GBAM, Mahendra G, **Premawardhena A, Mettananda S.** Acute on chronic osteomyelitis due to coliforms in a Sri Lankan child with homozygous sickle cell disease. Sri Lanka Journal of Child Health 2021; 50(3):
71. Yasara N, **Premawardhena A**, **Mettananda S**. A comprehensive review of hydroxyurea for β-haemoglobinopathies: the role revisited during COVID-19 pandemic. Orphanet J Rare Dis. 2021 Mar 1;16(1):114.

72. **Mettananda S**, Pathiraja H, Peiris R, Bandara D, de Silva U, Mettananda C, **Premawardhena A**. Maternal knowledge on curative therapies and its impact on medical care and psychological health among children with thalassaemia in Sri Lanka. Sri Lanka Journal of Child Health 2022; 51

Recognition of our research at Sri Lanka Medical Council (SLMA) Sessions

At the Thalassaemia Internationl Federation (TIF) Conference, Greece in 2017

A journey to Greece

Thalassaemia prevention programmes

Since 2018, onwards with direct involvement of the non-communicable division of the Ministry of Health in thalassaemia prevention, the role of our unit was specified as key to screening population in Gampaha district. Staff Grade senior nursing officer Mrs. Preethi Manel with the able support of other members of the unit conducted regular programmes across the region.

Thalassaemia Screening and Prevention Programme in a school

Our Research Collaborator Dr. Angella Allen from Liverpool, UK

Dr. Angella Allen at school thalassaemia screening programme

Transport for patients

We have a dedicated van (Managed by the University) and an ambulance (staffed by the Hospital) to look after the needs of the patients and the unit.

Table 6: Summary of Staff at Thalassaemia Care Centre

Staff members	2006-2011	2012 -2021
Medical officer	1	2
Nursing officers	1	10
Technical Officer	1	2
Development Assistant	1	1
Support Staff	0	5

Adult patient care provided under supervision of Senior Professor Anuja Premawardhena, Consultant in charge of thalassaemia care centre

Professor Anuja Premawardhena, Senior Professor, Department of Medicine, Faculty of Medicine, University of Kelaniya

Job title: Senior Professor/Consultant Physician/In charge thalassaemia care centre

Email: premawa@kln.ac.lk

Biography: Prof Anuja Premawardhena is a Senior Professor in the Department of Medicine of University of Kelaniya and was the founder of the Adolescent and Adult thalassaemia unit. He is an internal medicine specialist by training with an interest in Haemoglobinopathies and disorders of iron metabolism. He obtained a DPhil by research from University of Oxford in the field of Haemoglobinopathies. The research collaboration developed with Oxford UK and Toronto Canada are ongoing and have resulted in key studies relevant to thalassaemia in Sri Lanka including in the studies of Haemoglobin E β thalassaemia and Sickle Cell disease.

Education and training: MBBS (Perad'ya), MD (C'bo), MRCP (UK), FRCP (London), DPhil (Oxon), FCCP(SL), FNAS (SL)

Specialization: Internal Medicine

Research Interests:

- Haemoglobin disorders
- Iron metabolism

Paediatric care provided under supervision of Professor Sachith Mettananda at ward 23, North Colombo Teaching Hospital, Ragama

Professor Sachith Mettananda, Professor, Head of the Department of Paediatrics, Faculty of Medicine, University of Kelaniya

Job title: Professor/ Consultant Paediatrician

Email: sachith.mettananda@kln.ac.lk

Biography: Professor Sachith Mettananda is currently a Professor and the Head of the Department of Paediatrics at the University of Kelaniya and a Consultant Paediatrician at Colombo North Teaching Hospital, Ragama, Sri Lanka. He is also the paediatrician-in-charge of the Colombo North Paediatric Thalassaemia Centre and has several years of experience in managing patients with haemoglobinopathies. In collaboration with the Weatherall Institute of Molecular Medicine of the University of Oxford, he has conducted several pre-clinical and translational research studies on novel genetic-based approaches to treat thalassaemia, which include CRISPR genome editing.

Education and training: MBBS (C'bo), MD (C'bo), DCH (C'bo), Dphil (Oxon)

Specialization: General Paediatrics
Research Interests:

- Thalassaemia
- Anaemia
- Paediatric Red Cell Disorders

Endocrine support provided by Dr Dulani Kotthachchi

Dr Dulani C Kottahachchi, Department of Physiology, Faculty of Medicine, University of Kelaniya

Job title: Senior Lecturer (Grade II)/ Consultant Endocrinologist

Email: dulanik@kln.ac.lk

Biography: Dr. Dulani Kottahachchi is a Senior Lecturer and a Consultant Endocrinologist attached to the Department of Physiology, University of Kelaniya. She conducts the Endocrine Clinic at the Thalassaemia Care Centre at Colombo North Teaching Hospital for the patients with Endocrine problems related to Thalassaemia, such as hypogonadism, delayed puberty, hypothyroidism, diabetes mellitus, osteoporosis, hypoparathyroidism and hypocortisolism. She's a member of the International Study Group of Endocrine Complications in Thalassemia (I-CET) headed by Prof.Vincenzo De Sanctis in Italy. Her research interests include diabetes mellitus and metabolic bone diseases in thalassaemia.

Education and training: MBBS (Kel), MD (Col), MRCP (UK)

Specialization: Endocrinology

Research Interests:

- Endocrine complications in thalassemia
- Graves orbitopathy

Psychiatric support provided by Dr. Aruni Hapangama

Dr. Aruni Hapangama/ Head, Department of Psychiatry, Faculty of Medicine, University of Kelaniya

Job title: Senior Lecturer (Grade I)/ Consultant Psychiatrists

Email: ahapangama@kln.ac.lk

Biography: Dr Aruni Hapangama is attached to the Department of Psychiatry, Faculty of Medicine, University of Kelaniya as a Senior Lecturer. In addition, she works as a consultant psychiatrist at the University Psychiatry Unit of the North Colombo Teaching Hospital, Ragama. Dr Hapangama has a special interest in people with mood/ anxiety disorders and substance related issues. She is involved in research in the above areas.

Education and training: MBBS (Kel'ya), MD (C'bo), FRANZCP

Specialization: General Adult Psychiatry

Research Interests:

- Substance misuse / Psychiatric disorders in women

Haematological backing provided by Professor Senani Williams

Professor Senani Williams, Professor, Department of Pathology, Faculty of Medicine, University of Kelaniya

Job title: Professor/ Consultant Haematologist

Email: senaniw@kln.ac.lk

Biography: Prof Senani Williams is a member of the Department of Pathology of the Faculty of Medicine, University of Kelaniya. She is a specialist in Haematology by training with special interest in haemato-oncology and bio- dosimetry. Her research collaborations through a technical project of the International Atomic Energy Authority, helped set up the bio-dosimetry and cytogenetics laboratory. A National research council grant has helped set up further testing as well as set up further studies.

Education and training: MBBS (NCMC), Dip.Path. (C'bo), MD Haematology (C'bo), FRC Path (UK), FCCP

Specialization: Haematology

Research Interests:

- Chronic myeloid leukaemia
- Biodosimetry

Laboratory genetic assessments including other red cell disorder supported by Dr Shiromi Perera

Dr Shiromi Perera, Head/Department of Biochemistry and Clinical Chemistry, Faculty of Medicine, University of Kelaniya

Job title: Senior Lecturer (Grade I)

Email: shiromip@kln.ac.lk

Biography: Dr. Shiromi Perera is post-doctoral research fellow of Prof. Anuja Premawardhana and the in charge of the new red cell disorders diagnostic laboratory at the Adult and Adolescent Thalassaemia Care Centre at NCTH Ragama. She is a senior academic at the Department of Biochemistry and Clinical Chemistry, Faculty of Medicine, University of Kelaniya. Dr. Perera has obtained her B.Sc. Special degree in Molecular Biology and Biochemistry at the University of Colombo and obtained her PhD degree from University of Kelaniya in the field of molecular haematology. She had obtained an extensive training and experience in the field of molecular haematology at national and interactions institutions including, International Centre for Genetic Engineering (ICGEB) Italy, Weatherall Institute of Molecular Medicine, UK and Haematogenetic Laboratory at National Institute of Immuno-Haematology, India. Her primary research interests are on hemoglobinopathies, rare red cell disorder and genetic basis for unexplained anaemias.

Education and training: BSc (C'bo), MPhil (J'pura), PhD (Kel'ya)

Specialization: Molecular Medicine

Research Interests:

- Haemoglobin disorders
- Anaemia
- Iron metabolism disorders

Genetic counselling provided by Dr Padmapani Padeniya

Dr Padmapani Padeniya, Department of Anatomy, Faculty of Medicine, University of Kelaniya

Job title: Senior Lecturer (Grade II)

Email: padmapani@kln.ac.lk

Biography: Dr. Padmapani servers as a genetist at Adult and Adolescent Thalassaemia Care Centre and she conduct genetic counselling services in the centre. She has introduced prenatal screening and pre implantation genetic screening for thalassaemia patients to prevent the recurrence of thalassaemia status in their next pregnancies. Further, with the collaboration of Resonance Health, Australia, she has involved in establishing the Ferriscan service in Sri Lanka. This MRI technology is important for thalassaemia patients to assess their body iron overload through a non- invasive approach.

Education and training: MBBS(Pera), MSc in Clinical Genetics

Specialization: Clinical Genetics

Research Interests:

- Thalassaemia
- Reproductive Genetics
- Dysmorphology

Medical Officers of the Adult thalassaemia Centre (as at 2021)

Dr **A.M. K. R. Attanayake**, Thalassaemia Care Centre, North Colombo Teaching Hospital, Ragama

Job title: Medical Officer

Email: kumariatta67@gmail.com

Biography: Dr. Kumari is currently working as a senior medical officer at thalassemia care centre NCTH Ragama. She has obtained her MBBS degree at University of Ruhuna. She has 27 years working experience as a medical officer and she was fortunate to get working experience in special fields of medicine namely Anaesthesiology, Neonatology, Haematology, Rheumatology and Rehabilitation. After obtaining her diploma in family medicine, she moved to work as a medical officer in family medical clinic at BH Kiribathgoda. Her main interest is reading

Education and training: MBBS, DFM

Dr **Vidya Lanka Jayasinghe,** Thalassaemia Care Centre, North Colombo Teaching Hospital, Ragama

Job title: Senior Medical Officer (Grade I)

Email: vidyalankajayasinghe@gmail.cm

Biography: Dr. Vidya is a grade 1 Senior Medical Officer having 17 years of working experience in the fields of Surgical, Medical, Gynaecology and Obstetrics, STD, Prison, Adult and Child Psychiatry, Counselling and Psychotherapy. She has obtained her MBBS degree at University of Ruhuna and also completed a PG diploma in Psychiatry. She is specially trained in treating Behavioural and learning disorders in children. Dr. Vidya is currently involved in a self-study about the "Efficacy of nocturnal administration of Defarasirox in Thalassemia patients. Interested in Yoga, Meditation and Travelling.

Education and training: MBBS(Ruhuna), PG diploma in Psychiatry

Past Medical Officers

Dr. Ishari Silva is a registrar in Family Medicine at PGIM, University of Colombo and has worked as a medical officer in adult and adolescent thalassaemia care centre at North Colombo Teaching Hospital Ragama from 2007 to 2019. Dr. Ishari has obtained her Doctor of Medicine degree at Saint Petersburg I.P. Pavlov State University Russia and Diploma in Family Medicine at PGIM, University of Colombo Sri Lanka and MCGP degree at College of General Practitioners of Sri Lanka. She has obtained extensive training and experience in Managing Thalassaemia patients by working in the Thalassaemia unit for twelve years. She has published a patient education book for Thalassaemia patients in the country.

Dr. Nizri Hameed has obtained an M.B.B.S degree from the University of Kelaniya (Sri Lanka). Under the guidance of Prof. Anuja Premawardhana, had the opportunity to work as a medical officer primarily focused on the treatment and well-being of Thalassaemia patients, while participating in ongoing researches from 2014 to 2018. Creating awareness among the general public through lectures, media and also conducting screening programs among the youth were also performed with the help of the staff of Ragama Thalassaemia care centre.

Nursing Staff

Mrs. P.R.D.R. Piyatunga, Nursing Officer in Charge, Adults and Adolescent Thalassaemia Care Unit, North Colombo Teaching Hospital Ragama

Job title: Nursing Officer (Supra Grade)

Email: dpiyathunga@gmail.com

Biography: Mrs. Piyathuga has been working as the head nurse in the adult and adolescent thalassaemia care unit since 2011 to date. She has passed out from Nursing School Kandana with a diploma in nursing and started her nursing career in 1993. Since then, she had worked in several wards and units and had over 28 years' experience in nursing. She is committed to ensuring good patient and staff experience and to the development of the nursing workforce.

Education and training: Diploma in Nursing

Working experiences:

- Cardiothoracic ICU nursing (6 years)
- Gynaecological nursing (3 years)
- Post-natal nursing (3 years)
- OPD /surgical ward (6 years)
- Thalassaemia care centre (10 years)

Miss D.M.W.Dodammulla

Job title: Nursing Officer (Supra Grade)

Education and training: Diploma in Nursing

Working experiences:

- Eye ward (10 years)
- Medical nursing (3 years)
- Surgical nursing (2 years)
- Thalassaemia care centre (10 years)

Mrs. A.K.P. Manel

Job title: Nursing Officer (Grade I)/In charge of thalassaemia screening and prevention programme
Email:

Education and training: Diploma in Nursing

Working experiences:

- Orthopaedic ward (2 years)
- Medical nursing (10 years)
- Health Education (4 years)
- Thalassaemia care centre (10 years)

Mrs. K.S. Thilangani

Job title: Nursing Officer (Grade I)

Email: ksthilangani@gmail.com

Education and training: Diploma in Nursing

Working experiences:

- Surgical nursing (12 years)
- Medical nursing (2 years)
- Orthopaedic ward (2 years)
- Thalassaemia care centre- Since April 2021

Mrs. R.M.M.D.T. Rajapakse

Job title: Nursing Officer (Grade II)

Email: megharajapaksha9@gmail.com

Education and training: Diploma in Nursing

Working experiences:

- Surgical ward (1 year)
- Medical nursing (1 year)
- Paediatric nursing (2 year)
- Genito-urethro ward (6 year)
- Gyn ward (1 year)
- Thalassaemia care centre (3 year)

Mrs. J.A.S. Priyangika

Job title: Nursing Officer (Grade II)

Email: priyangikashyamali304@gmail.com

Education and training: Diploma in Nursing

Working experiences:

- Medical nursing (1 year)
- Paediatric nursing (1 year)
- Orthopaedic nursing (3 years)
- Thalassaemia care centre (2 years)

Mrs. P.A.C.K. Gunathilaka

Job title: Nursing Officer (Grade II)

Email:

Biography: Mrs. P. A. C. K. Gunathilaka had followed the Diploma in Nursing Course in Nursing Training School at Kandana and passed out in 2007. She has past six years' experience in nursing at the ICU & haemodialysis unit. Mrs. Gunathilaka has been working as a nursing officer attached to thalassemia unit since 2016. She is a health education license nursing officer. She had followed the DENO training programme on health ministry. Her ambition is to improve her knowledge by attending the research.

Education and training: Diploma in Nursing

Working experiences:

- ICU and haemodialysis Unit (6 years)

Mrs. P.W.P.S. Pathiraja

Job title: Nursing Officer (Grade II)

Email: nuwan.prabodha@gmail.com

Education and training: Diploma in Nursing

Working experiences:

- Thalassaemia care centre (7 year)

Mrs. S.I.N. Kumari

Job title: Nursing Officer (Grade II)

Email: inokanadee654@gmail.com

Education and training: Diploma in Nursing,
BSc. Nursing (University of Sunderland UK)

Working experiences:

- Thalassaemia Care Centre (7 years)

Mrs. M.A.N Nalani

Job title: Nursing Officer (Supra Grade)

Education and training: Diploma in Nursing

Working experiences:

- Paediatric nursing (3 years)
- Neuro surgical (12 years)
- ICU (3 years)
- Medical nursing (2 years)
- Surgical nursing (2 years)
- Gyn ward 6 months
- Thalassaemia care centre -10 yrs

Laboratory Staff

Mr. Lakshman Perera, Department of Medicine, Faculty of Medicine, University of Kelaniya

Job title: Staff Technical Officer (Grade II)

Email: lakshma@kln.ac.lk/hlakshmanp@gmail.com

Biography: Laxman: A long standing employee of University of Kelaniya who has completed more than 30 years of service in the Faculty of Medicine. He was promoted as a Technical officer in 2003. He was the first technical officer of the diagnostic laboratory which began in 2003 and had a brief stint of training in University of Oxford Weatherall Institute of Molecular Medicine in 2007.

Mr. Rexan Rodrigo, Thalassaemia Care Centre, North Colombo Teaching Hospital, Ragama

Job title: Development Assistant

Email: rexanr@yahoo.com

Biography: Mr Rodrigo had his undergraduate training in the stream of physical science has re trained himself to work in Molecular biology. He specializes in the diagnosis of alpha thalassaemia and successfully completed an M.Phil. in 2015. He has over 15 international publications and has won several awards including Presidential award for research in 2016.

Education and training: BSc. (Kelaniya), MPhil (Kelaniya)

Specialization: Molecular Biology

Research Interests:

- Thalassaemia

Mrs M.G.C. Nirmani Wickramasinghe, Thalassaemia Care Centre, North Colombo Teaching Hospital, Ragama

Job title: Medical Laboratory Technologist

Email: chathurikanirmani47@gmail.com

Education and training:

Higher Diploma in Medical Laboratory Technology

Undergraduate - Bachelor of medical Lab Science (honours) Faculty of Health Science, OUSL

Working experience:

- Base Hospital Kahawatta (2 Years)
- Institute of Legal Medicine and Toxicology (JMO's office), Colombo - Histology lab (2 Years)
- MRI virology section - Molecular lab (6 Years)

  PCR testing for JE, HSV, INFLUENZA, DENGUE, ZIKA and WEST NILE viruses, Dengue serotyping, ELISA for antibody testing

  Served as MLT WHO surveillance programmes JE, Dengue and Rota Viruses
- Thalassaemia Care Centre (3 years)

Health Assistant Staff

Mrs. B.N. Nbalasooriya

Title: Health Assistant

Email: nbalasooriya66@gmail.com

Education and training: Passed G.C.E. (O/L)

Working experience:

- Served as a health assistant for 16 years

Mr. Maju Prasanna Liyanage

Title: Health Assistant

Email: maju.liyanage@gmail.com

Education and training: Passed G.C.E. (O/L)

Working experiences:

- Served as a health assistant for 19 years

Mr S.M.C. Fernando

Title: Health Assistant

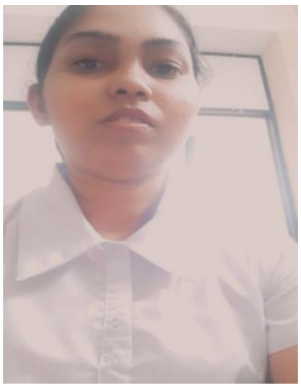
Email: mihiruc5@gmail.com

Education and training: Passed G.C.E. (O/L), Sat for G.C.E. (A/L)

Working experiences:

- Served as a health assistant for 9 years

Miss. A.V.G.P.Somarathne



Title: Health Assistant

Email: gpriyadarshani68@gmail.com

Education and training: Passed G.C.E. (O/L) and G.C.E. (A/L)

Working experiences:

- Served as a health assistant for 7 years

Miss M.D.S.Dissanayake

Title: Health Assistant

Email: diharasammani23@gmail.com

Education and training:

Passed G.C.E. (O/L) and G.C.E. (A/L).

Undergraduate - BA degree in sociology and environmental studies at the University of Sri Jayewardenepura.

Working experiences:

- Served as a health assistant for 2 years