

Communication on Engagement (COE) Report

This COE describes the Chronic Care Center's efforts in supporting the implementation of the ten principles and in contributing to achieving SDGs as well as the progress made during the previous two years after joining the Global Compact Network.

Period covered: 2022-2023

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This COE describes the Chronic Care Center's efforts in supporting the implementation of the ten principles and in contributing to achieving SDGs as well as the progress made during the previous two years and after joining the Global Compact Network.

Overview:

The Chronic Care Center is a medico-social institution, specialized in the treatment and follow-up of childhood chronic diseases: Thalassemia and Type I Diabetes.

The Chronic Care Center is the first philanthropic medical institution of its kind in Lebanon and the Middle East. Founded in 1992 and officially inaugurated in June 1994

Mission:

The Chronic Care Center is a non-governmental, non-profit organization striving to lead specialized care for children with insulin-dependent Diabetes and Thalassemia by providing excellent, comprehensive, and accessible services and research for Lebanon and the region.

Keeping abreast with developments in clinical research, the Center also worked with great efforts to promote its preventive role. Through its educational programs and awareness campaigns, the Center aims to increase the understanding of diseases, reduce risks and complications and contribute in building up healthy generations.

Major activities:

The Center provides persons with Insulin dependent Diabetes and Thalassemia with a high quality therapeutic surveillance, a strict medical follow-up and a regular psychosocial orientation under the supervision of a multidisciplinary team of specialized doctors, nurse educators, social workers and a dietitian. This unique approach empowers patients and their families to accept their chronic condition and learn how to deal with it. It offers them also with the necessary medication and material needed for their treatment.

The Center also supports research in the field of chronic disease.

The Center collaborates with the Ministry of Public Health, other ministries, scientific societies and different parties to promote awareness about the disease and contribute to its prevention through different initiatives in different regions of the country.

Values:

The Center supports the ten principles of the UN with respect to human rights, labor and environment and anti corruption.

Its humanitarian mission is founded on the basic right of every child to a better health.

Individuality, dignity of patients, differences and diversity are respected

Equity and confidentiality in health care are also honoured.

An institutional review board (IRB) is designated to protect the rights, safety and well-being of humans involved in a clinical trial or research.

The contribution of the Centre towards achieving SDGs:



The Main SDG of the Center is SD3: Good Health and Well Being

A- Activities aiming at Good Health and Well Being at patient Level

Good Health of patients

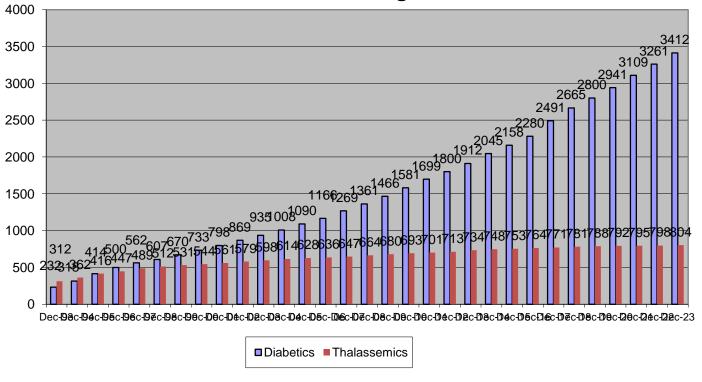
During the period 2022-2023, *The Center provided on yearly basis more than* 2500 persons with Insulin dependent Diabetes and Thalassemia with a high quality therapeutic surveillance, a strict medical follow-up and a regular psychosocial orientation under the supervision of a multidisciplinary team of specialized doctors, nurse educators, social workers, a dietitian and a psychologist. This unique approach empowered patients and their families to accept their chronic condition and learn how to deal with it. The Center has offered them also with the necessary medication and material needed for their treatment.

A 24hr support hot line is at the disposal of the patient with Diabetes as well as a line for educational support.

An echocardiography service was introduced in 2019 to provide patients with high quality free service since cardiac complications are common and cause of death in patients with Thlassemia.

The number of registered persons with Type 1 Diabetes reached 3412and 804 with Thalassemia at the end of 2022.





Well being of patients

The Center aims at improving the well being of persons with Type 1 Diabetes and Thalassemia by offering them a psycho-social follow up and by organizing activities that contribute to their empowerment and to a better quality of life.

Summer Camps:

Due to Covid 19, the Center could not organize its usually yealy summer camp for youngsters with Type 1 Diabetes in 2022 but could organize its 23 rd summer camp in July 2023 in Zahle.

The Center could organize a Summer camp in July 2023 for youngsters 9-12 years old in Zahle.

It is worth mentioning that patients were supervised by a medical team but the recreational program was delivered by young leaders, older patients with Type 1 Diabetes.

23 rd summer camp summer 2023







Recreational and educational Activity for patients:

Recreational day for children with Type 1 Diabetes - Visit of Diala Erslan library and Castle on June 2023

Educational and recreational day for T1 D children age 8-12 at amusing Center including:

- Listening to story telling
- Visit of a special Library
- Visit of the Castle
- Sharing a meal

Counting Insulin according to test and meal and validating counting insulin by nurses







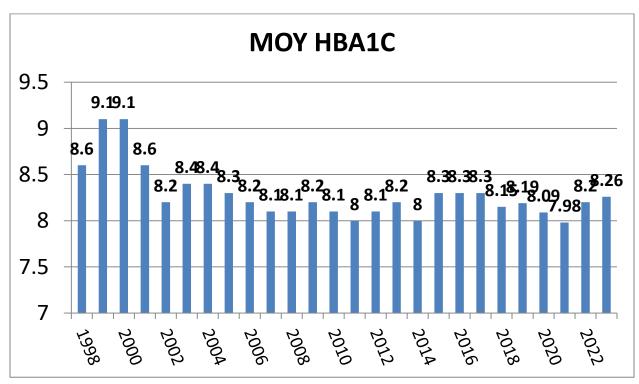
Recreational day for patients in the occasion of Diabetes Day





A- Outcomes

1. Good HBA1C levels for patients reflecting good management of their Diabetes



2. Patients better self management, care, and social integration at the end of the day camps and activities .

An increased number of patients who can do their tests and inject themselves with insulin and they have a better understanding of disease.

An increased number of patients who can talk openly about their disease A better social integration

- 3. The Center is recognized as a Center of Excellence
 - a. The center is recognized by the International Diabetes Federation (IDF) as a Center of Excellence for the years 2022-2023



4. Award received from Lebanese Society of Endocrinology Diabetes and Lipids

The president of the Chronic Care Center has received an award during the Diabetes Day Conference jointly organized by the Lebanese Scientific Society and the Center.

The Award was bestowed to Mrs Mouna Haraoui by the Lebanese Society of Endocrinology Diabetes and Lipids and in the presence of a representative of the Minister of Public Health for her **remarkable efforts and dedication to diabetes care, bringing hope and healing to countless lives.**

This award recognized her efforts in establishing the Chronic Care Center and securing that patients with Type 1 Diabetes receive the high quality comprehensive care needed.



B- Activities aiming at Good Health and well being at Parents Level

Parents support Sessions

Parent Support sessions for parents of newly diagnosed patients with Type 1 Diabetes

Parent support sessions are done to help families cope with the new condition of their child and to maintain healthy family dynamics on routine basis. This year a parent support session was done in parallel to the summer camp

Parents had the chance to discuss their worries and inquiries . Young leaders could help bring the patient perspective.



C- Activities aiming at Good Health at Community Level

National Thalassemia Prevention Program:

Through its national prevention program in partnership with the Ministry of Social Affairs, the center could decrease the number of patients with Thalassemia a chronic condition that requires a lifelong costly treatment and puts a heavy burden on the patient/family and society.

Unfortunately due to Covid 19 many activities were postponed

Outcomes

1. On- going Comprehensive Program

Awareness Campaigns at the national level

• Around 5000 persons per year are attending these sessions (villages, schools, universities)

Training of trainers

• Additional 100 professionals are trained as trainers per year to promote awareness in their community

• Production and dissemination of educational material

Free screening to identify new carriers

- General population (schools, universities)
- High risk group (brothers/sisters, cousins, family members)
- Prenatal diagnosis in genetics laboratory
- •Genetic testing of CVS or amniotic fluid
- Pre-implantation genetic diagnosis for beta thalassemia

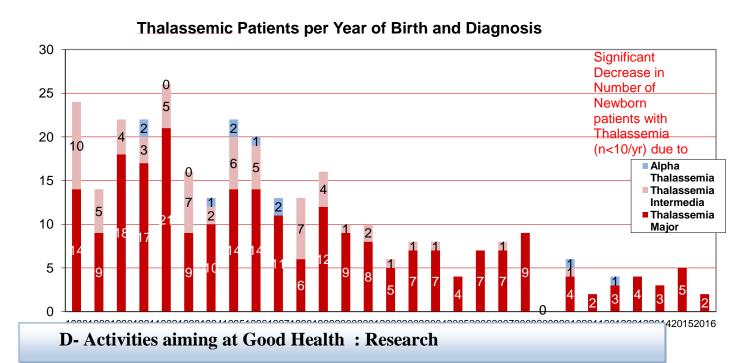
Updated registry of carriers at the center

Counseling of identified carriers

2. Activities all over Lebanon



3. Significant Decrease of more than 75 % of new cases with Thalassemia



- The Center is involved in many international clinical trials

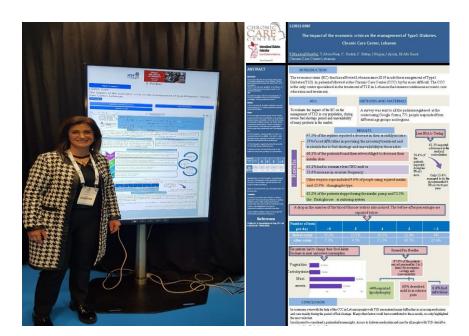
Outcomes

The findings contributed to a change in the treatment modalities of Thalassemia Intermedia a condition only common in our region and contribute to the registration of new medications that improve the care of patients with Thalassmia . It also contributed to change in the international guidelines for NTDT patients (intermedia)

- The Center is also involved in multidisciplinary research.

The impact of the economic crisis on the management of Type1 Diabetes was studied during fuel shortage period.

Outcomes



Abstract was accepted in IDF annual congress 2022 and was selected for oral presentation

E- Activities aiming at Health and Well Being of Employees

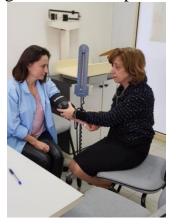
Wellness program for employees:

The program was introduced in February 2018 but some activities were freezed in 2020 due to Covid 19.

The program aimed at preventing Diabetes & other chronic conditions among employees and to improve their overall health condition.

- -It consisted of medical assessment by an endocrinologist and medical laboratory tests including fasting blood glucose, glucose tolerance test and HBA1C, lipid profile and others.
- -A dietetic assessment including body fat composition and follow-up by a dietitian was provided.
- -A fitness assessment and fitness classes were offered twice per week within working hours by professional trainer.

The medical followup is still maintained but the fitness classes were postponed due to Covid 19 pandemic. We are still providing free of charge consultation and glucose free strips for employees with diabetes and at risk of developing diabetes.









1. Patient/ Parent Education as part of comprehensive care

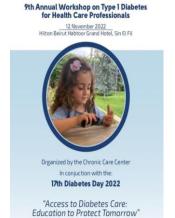
-Doctors, nurse educator dietitian offer medical education to patients and parents to empower them to manage better their disease .They offer one to one education as well as group education . During Covid 19 the Center had to find new ways to educate patients through offering virtual educational consultation

Outcomes

Virtual consultations during Covid 19 could maintain good Diabetes control among patients as described in abstract presented in IDF 2021congress. This method was introduced as a regular method after covid 19. A special whatsapp line is dedicated for patient educational inquiry .

B- Health Care Professionals Education

- 1. The center organizes an annual workshop for school and hospital nurses , nurses or /& dietitians on Diabetes aiming at spreading better knowledge about practical management of disease
- -November 2022, 9th annual workshop for school nurses professionals for 40 participants







- November 2023 , $10^{\rm th}$ annual workshop for hospital nurses for 40 participants





Outcomes

Better knowledge about management of Diabetes in School or hospital for newly diagnosed patients. Nurses are important elements in the circle of care of patients with type 1 Diabetes.

2. Continuing education for the Center staff

-Lecture on pump therapy for nurses October in 2022:





-Lecture on Degludec to Nurses in 2023:



3. Participation in National Conference on NCD and a conference about Children in Danger in Lebanon





Outcomes

Awareness about the Center and its services as well as importance of SDG3

C- Community awareness

The center contributes to community awareness about the diabetes and Thalassemia.

1. The Center offered screening to KPMG employees for two consecutive years .

Free Glucose and HBA1C testing were offered . Hypertension screening was also done and medical advice was given

Outcomes

This activity could provide people with free testing, education and orientation to specialized doctor. It could also identify new persons with risk for diabetes and hypertension thus early diagnosis prevents complications.

We could also promote UN global compact and SDG3



Campaign 2023



Campaign 2022

2. The Center offered community screening in university set up .

Free Glucose testing were offered to students and staff in balamand university in 2022 during the annual balamand NGO Fair

Outcomes

This activity could students and staff with free testing, education and orientation. . We could also promote UN global compact and SDG3 as seen in picture







3. Live Facebook session on Nov 12, 2023 on importance of access to Diabetes Care :







Innovative ways in preventing Diabetes introduction of wellness programs in work place (Activity aiming at Good Health and Well being among employees)

Project described in SDG3 section

Outcomes



Better health, quality of life and work environment

Aim at spreading this experience among business partners and through the Global

Young leaders Support: Peer support

The body of young patients with Type 1 Diabetes still supports younger patients

Outcomes

- -Involvement in summer camp
- -mentoring /role models to younger
- -Involvement in awareness session
- Better social integration and management of disease by younger patients





The Center alleviates the financial burden of the cost of the treatment of the disease by providing subsidized treatment Cost of the treatment per patient with Type 1 Diabetes per year is around 2000 \$-5000 \$

Cost of treatment per patient with Thalassemia per year ranges between 10000 \$ - 30000 \$

Provision of subsidized medication and material needed for treatment of patients (free of charge medication distributed)

It is worth mentioning that Lebanon's recent crisis affected the health care system, serious issues related to availability and affordability of products are faced by patients. The Center struggled to maintain continuous supply to patients and advocated for the importance of access to insulin and other vital products for PWD. It could manage through collaboration with WHO, LFAC, Direct Relief and other international donors. For instance the severe crisis led to severe devaluation of local currency ex: Minimum salary has been changed from 500 usd to almost 90 usd). The local currency has been devaluated by more than 60 folds (100 usd in local currency in 2019 is less than 2 dollars today in 2023)

Total Distributed in 2023:

Diabetes material distributed in 2023 worth more than 1.2 Million USD

92771 insulin pens/ vials

29339 Glucose strips

Syringes and pen needles 223792

Material and medication were also distributed to patient with thalassemia in 2023 worth more than 250000 USD.

Outcomes

Patient contributes with symbolic amount thus this support reduces the financial burden on the family and contributes to prevention of poverty among families with scarce or limited resources. Additional support was highly appreciated during severe economic crisis that reduced drastically the purchasing power of people.



Economic inequalities

Patient's equity is one of the values adopted at the center. All patients have the same right to receive medical care irrespective of social or economic level

Outcomes

Quality treatment is provided to all persons equally.

Social integration and Patient access to medical care

The center works hard at promoting the productive image of patients with Type 1 Diabetes and Thalassemia in order to reduce social inequalities .

In 2022 and 2023 in the occasion of World Diabetes Day and in view of the economic crisis and unavailability of medicine, the Center campaigned for access to care through a TV spot and several TV and Radio interviews involving Doctors, administrators, nurses, patients with Type 1 Diabetes

2022





2023



-Involvement of patients in TV awareness sessions

Patients talking about their daily challenges and about their productive life

Outcomes

More awareness about the disease, its prevention and and its challenges. It reduces inequalities and promotes more integration of patients in society.



Community support to needs of other citizens: Blood Donation

The center works hard at promoting the importance of blood donation among citizens through community activities and blood drives

On the occasion of World Thalassemia Day, the Chronic Care Center, in collaboration with the Lebanese Red Cross has organized a blood donation campaign in Ain El Mreisseh.

Outcomes

Blood donation Campaign could raise awareness on importance of blood donation in General and for Patients with Thalassemia. TV coverage of the event could also increase the reach. Famous actor Dory Samarani could also invite people to donate blood like he did for persons with Thalassemia.

Around 100 units were collected









Recycling of regular and medical waste

The center recycles all its medical waste and some of the patients medical waste Through Arcenciel (another member of Global Compact Network Lebanon)

Outcomes

7211 Kg of medical waste were recycled through another GNL partner Arcenciel 2022-2023 (3199 kg in 2020 and 4012 Kg in 2023). This cost the center more than 4500 USD per year .

The Center also recycles other waste like paper, plastic and others.

Education on proper recycling

Teaching patients how to recycle their medical waste and to dispose of needles safely

Outcomes

Safety disposal of medical waste at the home level.

Patients were invited to return their empty medical vials and boxes to the Center who will take care of proper disposal through our Medical waste subcontractor.

Responsible consumption

Administrative control on the necessary consumption of free medication is done to avoid over consumption by requesting empty vials of some expensive medication.

Outcomes

Optimal use of free medication and prevention of unused expired medication.



The Center has partnered with many bodies for better achievement of its goals. The Center usually perform many activities in collaboration with the Ministry of Public Health, the Ministry of Social Affairs and other bodies like Cities Changing Diabetes. Due to Covid 19 some activities were restricted.

Partnership with International Bodies: International Diabetes Federation (IDF)

The Center has been a member of the International Diabetes Federation .It participates in regional meetings as well as international congresses

Outcomes

The Center has been acknowledged as Center of Excellence for Care &Education

- Yearly celebration of World Diabetes Day following the IDF theme. Many activities are organized by the Center and shared with the network of other members of the Federation. It includes workshops, lighting the Center in blue, TV awareness interviews etc...

Partnership with International Bodies: International Thalassemia Federation (TIF)

Representation of the Center by a board member, Michele Abi Saad in the TIF

Exchange of expertise and representation of the region

Participate in founding an Arab Forum for Thalassemia associations under TIF umbrella

On- line Educational platforms made available for patients

Partnership with Scientific Society: Lebanese Society of Endocrinology Diabetes and Lipids

The Center participates on a yearly with the Society in a public conference in the occasion of World Diabetes Day. It participated in its 17 and 18th Conference in Nov 2022 and Nov 2023

Outcomes

Complimentary role between different stakeholders in the country to achieve common goals.

Partnership with International Bodies: WHO, Life for a Child and Direct Relief

It is worth mentioning that Lebanon's recent crisis affected the health care system, serious issues related to availability and affordability of products are faced by patients. The Center struggled to maintain continuous supply to patients and advocated for the importance of access to insulin and other vital products for PWD. The Center could manage through collaboration with WHO, LFAC, Direct Relief and other international donors specially that its financial reserves were trapped in the bank and inaccessible.

Outcomes

Availability of medication and provision of free medication and material needed for treatment of patients