

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: 2020-2021

Tal	ble	of Content:	
	>	Overview	p.1
	>	Mission	p.1
		Major Activities Values Contribution to SDGs and related Outcomes:	p.2 p.2
	>	SDG3: Good Health and Well Being A. Activities aiming at Good Health and Well Being at patient level B. Activities aiming at Good Health and Well Being at parents level C. Activities aiming at Good Health and Well Being at Community level	p. 6
		D. Activities aiming at Good Health: ResearchE. Activities aiming at Good Health and Well Being of employees	p.9 p.10
	>	SDG4 : Good Education	
		A. Patient/ Parent Education	p.11
		B. Health Care Professionals Education	p.12
		C. Community awareness	p.12
	>	SDG9 : Industry Innovation and Infrastructure	p.14
		SDG1 : No Poverty	p.16
		SDG10: Reduced Inequalities	p.18
		SDG11: Sustainable Cities and Communities	p.19
		SDG12: Responsible consumption and Production	p.20
			p.21



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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 2020-2021, *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 and a dietitian. This unique approach empowered patients and their families to accept their chronic condition and learn how to deal with it.

The Center offered them also the necessary medication and material needed for their treatment.

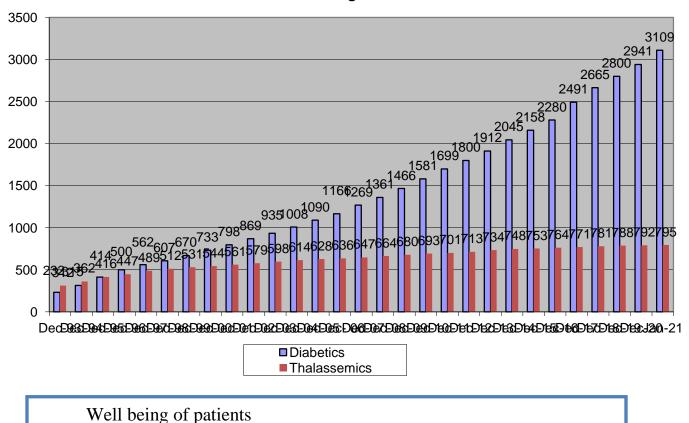
A 24hr support hot line is at the disposal of the patient with Diabetes

A Bone Marrow transplant program is sponsored by the Center to provide eligible patients with Thalassemia with permanent cure.

An echocardiography service introduced in 2019 is still beingoffered to patients It provides them with high quality free service since cardiac complications are the most common and the leading cause of death in patients with Thalassemia.

The number of registered persons with Type 1 Diabetes reached 3109 and 795 with Thalassemia at the end of 2021.





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/ Day Camp:

Due to Covid 19 Pandemic, the center could not organize its usual yearly summer camps for youngsters with Type 1 diabetes in 2020 and 2021.

The Center could organize a day Camp in October 2021 for youngsters 9-11 years old at the Center. The activities included games on healthy eating given by dietician, activity on how to express feelings and emotions given by social service, a motivational talk by older patient with Type 1 D and a Diabetes Challenge game given by nurses.



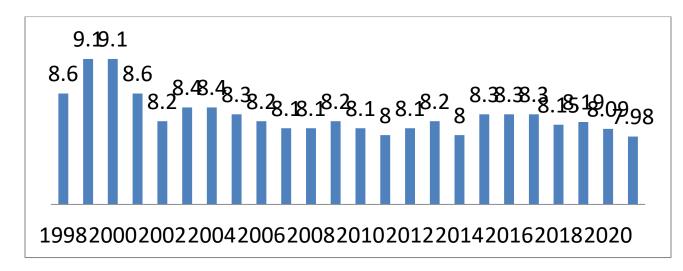






Outcomes

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 2020-2021



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. The activities were suspended due to Covid 19 pandemic.

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.

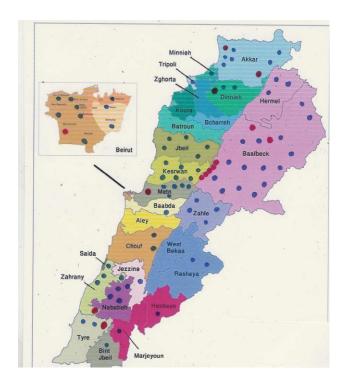
Unfortunately due to Covid 19 many activities were postponed

Outcomes



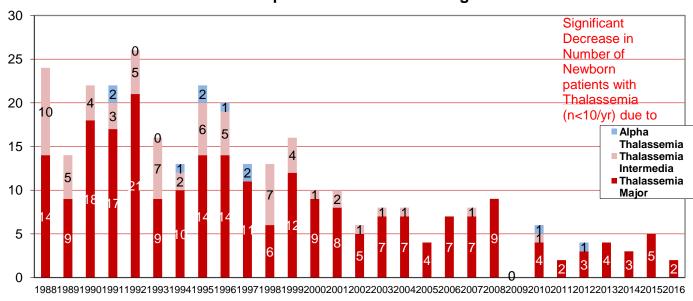
- Awareness Campaigns at the national level
- Around 5000 persons per year are attending these sessions (villages, schools, universities)
- Training of trainers
- Additional 100 professionals are trained as trainers per year to promote awareness in their community
- Production and dissemination of educational 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

Thalassemic Patients per Year of Birth and Diagnosis



D- Activities aiming at Good Health: Research

- The Center is involved in many international clinical trials

Outcomes

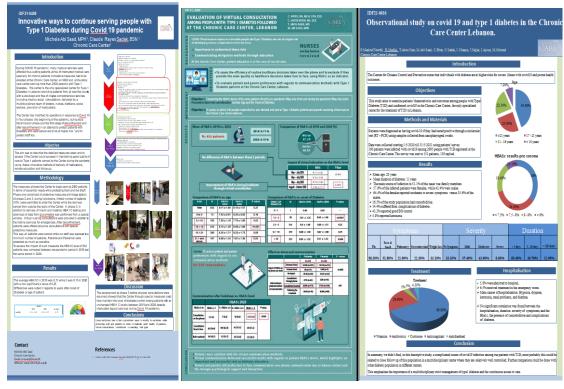
The findings contributed to a change in the treatment modalities of Thalassemia Intermedia a condition only common in our region and contribute to the registration of new medications that improve the care of patients with Thalassmia

- The Center was also involved in Research related to COVID 19

Outcomes

Abstracts accepted in IDF annual congress

- 1. Innovative ways to continue serving people with Type 1 Diabetes during Covid 19 pandemic
- 2. Evaluation of virtual consultation among people with T1D followed at Chronic care Center
- $3.\;\;$ Observational study on Covid 19 and type 1 diabetes in the Chronic Care Center Lebanon.



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









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 maintain good Diabetes control among patients as described in abstract presented in IDF 2021congress.

-Patient education on Thalassemia and Covid 19 was done through a webinar on including information on different vaccins, Covis and Thalassemia, challenges during the pandemic on May 2021

2. Diabetes Management and Capacity building workshop for young leaders with Type 1 Diabetes on Nov 2021



A- Health Care Professionals Education

Annual workshops on Diabetes

The center organizes a free annual workshop for school nurses, nurses or /& dietitians on Diabetes aiming at spreading better knowledge about practical management of disease

- -Jan 2020, 6^{th} annual workshop for healthcare professionals for 90 participants at the Center .
- Nov 2020 , $7^{\rm th}$ annual virtual workshop for healthcare professionals for 100 participants
- Nov 2021 , 8^{th} annual virtual workshop for healthcare professionals for 100 participants



C- Community awareness

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

1. The Center offered community screening in affected area of Beirut blast.

Free Glucose and HBA1C testing were offered to inhabitants of the area.

Outcomes

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

We could also promote UN global compact and SDG3 as seen in picture



2. Live Facebook session on Nov 6, 2021 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 Compact Network after Covid 19 Pandemic .

Innovative ways to keep serving patients with Diabetes during Covid 19 and specially period of Lockdowns

Despite Covid 19 pandemic, the Center provided more than 2000 patients with comprehensive treatment. It included multidisciplinary follow-up

(physical and virtual), 24hr hotline support and material and medication needed (insulin, glucose monitoring, glucagen etc...).

The Center had to use innovative ways to keep supply of medications uninterrupted especially at the beginning of the pandemic and during lockdown periods. Patients were served from outside the walls of the Center. Measures were described in abstract submitted during IDF Congress 2021





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 (sometimes free of charge)

Grand Total Distributed in 2020-2021:

172728 insulin pens/ vials

46778 Glucose strips:

- Out of which completely free of charge during 4 months of lockdown April-July2020

(~30211 vial/pen insulin and 8323 boxes of strips free of charge)

Material and medication were also distributed to patient with thalassemia.

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 lockdowm period

Support Community After Beirut Port Blast

Patients and Chronic Care Center's staff distributed in kind donation to people affected with Beirut Port Blast







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.

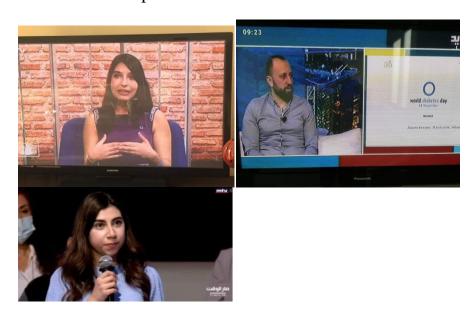
Social integration and Patient access to medical care

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

In 2021 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



-Involvement of patients in TV awareness sessions



Patients talking about their daily challenges and about their productive life

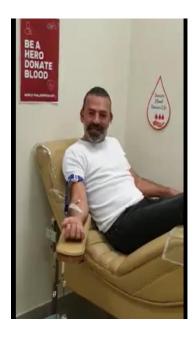


Community support to needs of other citizens: Blood Donation

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

A- Outcomes

Increased awareness about the need to support patients spread by celebrities.



Blood donation Campaign on June 2020 on the occasion Blood Donation Day . Video by celebrity , actor Dory Samarani inviting people to donate blood like he did for persons with Thalassemia. The video was posted on social media .





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

4817 Kg of medical waste were recycled through another GNL partner Arcenciel 2020-2021 (2151kg in 2020 and 2666 Kg in 2021)

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 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 15 and 16th Conference in Nov 2020 and Nov 2021

Outcomes

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