Building together

How engaging patient organizations make us better at adding value not just for us, but also for people living with diseases and for the society

Chiesi

Shared value project
report 2023

Contents

What is shared value?

Creating shared value

Our business model is based on the *shared value* principle: we aim to create economic value in a way that also creates value for society by addressing its needs and challenges. Success, for us, is making a positive imprint on the world.

Our why: because we can

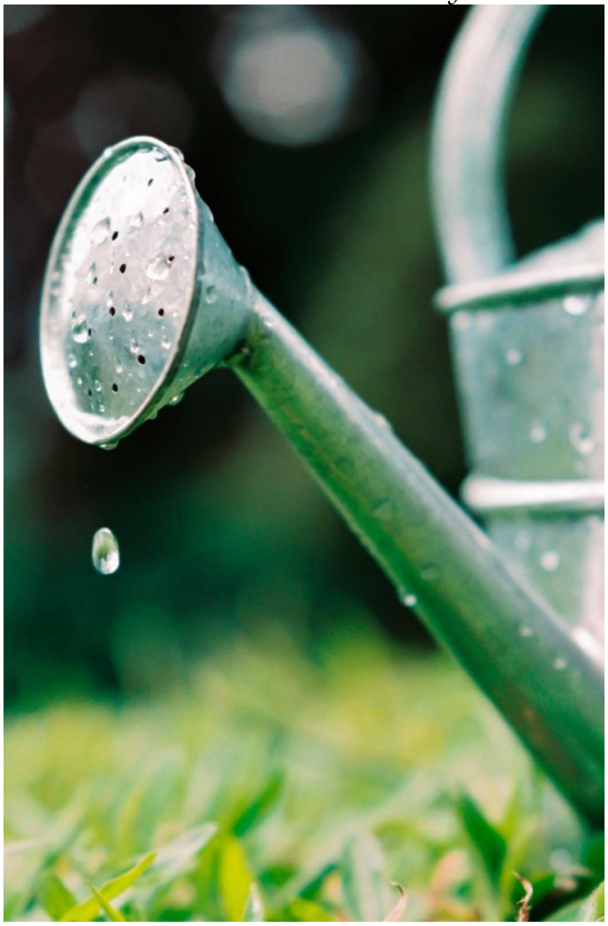
Being a family-owned company, we are committed to the long-term sustainability of our operations. Obviously, delivering medicines is our core business, and we reinvest 1/5 of our turnover in research and development to find new treatments for unmet medical needs. But we want our contribution to society to be greater than the sum of our medicines. If we can also help solve societal challenges, social and environmental needs, why shouldn't we?

We want to be a positive force in society. Because we believe we can. We believe we do.

Our "how"

We have embedded 9 of UN's global sustainability goals from Agenda 2030 in our strategic plan for the company. We look for win-win projects where we believe we can make a positive contribution to society. Here are some concrete examples of what we have done in the Nordic region.

We aspire to add value to the society we live in.



Nordic Fabry Digital Content board

Background Fabry

Fabry disease is a rare lysosomal storage disorder, with approximately 470 patients diagnosed in the Nordics[1]. Symptoms vary with age, sex and between individuals but typically present in multiple organs such as heart, kidneys, nervous system etc. As the gene causing the disease is located on the X-chromosome, men are more often severely affected than women.

The need

In lack of access to patient friendly disease information, Chiesi sought to fill the need by developing a web page for patients. Based on input from patients in an advisory board in 2021, this web page – rethinkfabry.se - was developed in co-creation with the Swedish patient association and Professor Andreas Kindmark. This web page has also been made available in other Nordic languages.

Continuous improvements

To ensure that the web page continues to stay relevant and answer to actual needs, a content board was installed to collect feedback and suggestions for improvement in a structured way. The board meets twice yearly. Suggested improvements from the June meeting with patient representatives from Sweden, Norway and Denmark include:

- Updated symptom checklist
- Development of patient stories
- Adding a video with psychologist on how to cope with a chronic disease.

Social value

Supporting persons living with Fabry disease to cope with/ develop strategies to handle the disease.

3 GOOD HEALTH AND WELL-BEING

Where:
Nordic

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[1] Estimate based on feedback from treating physicians in respective Nordic country (2023)

Mitochondrial Day 2023

Background LHON

LHON (Leber's Hereditary Optic Neuropathy) is a rare genetic mitochondrial disease, caused by DNA-mutations and mitochondrial dysfunction. People with LHON experience a sudden and painless loss of central vision leading to severe visual impairment or blindness. Mitochondria is the so called "powerhouse of the cell", responsible for creating 90% of the energy needed for organ function. Therefore, the most energy-consuming organs are the most affected by mitochondrial diseases. For example: brain, muscles, eyes. When exercising, new mitochondria are formed, and the damaged ones are repaired/eliminated.

The need

To improve the knowledge of the LHON patients and their families on the LHON disease and raise awareness of the disease in the general public.

How can we help?

In the Global Mitochondrial Disease Awareness Week 2023, Chiesi organized, in collaboration with LHON Eye Society, a conference to lift both the perspective of healthcare providers and of the LHON patients. In connection to the conference, a race was held at Hagaparken, Stockholm, to further raise awareness of the disease, and to promote an active lifestyle, as exercising has a positive impact on mitochondrial diseases.

Social value

- Improved management and capacity to cope with disease and increased understanding for the urgency of getting diagnosed.
- Increase awareness of the importance and benefits of regular physical activity.
- Shorten patient delay to diagnosis.

3 GOOD HEALTH AND WELL-BEING

17 PARTNERSHIPS FOR THE GOALS

Where:
Sweden

Nordic LHON advisory board

Background

Getting a correct diagnosis of LHON (see previous page) and appropriate care can be a lengthy process. Both persons living with LHON and carriers often develop depression. The disease brings challenges across several domains: physical capabilities, emotional well-being, interpersonal relationships, work and studies, income, and recreational activities.

The need

To understand the priorities for people living with LHON in the Nordics and to learn what changes would be most impactful on their lives. With this objective, Chiesi organised an online advisory board for people living with LHON.

How can we help?

Chiesi can help leverage information about patient's needs in our interactions with healthcare professionals, clinics, healthcare organisations, patient associations. The discussion provided three main insights:

- The right to live a full and normal life, despite the disease (not being defined by a diagnosis)
- Wish for expert centres for LHON/mitochondrial diseases in the Nordics
- Improved disease awareness would facilitate inclusivity in society.

Social value

A better understanding of the disease among the patients and their families will contribute to improved management and capacity to cope with their condition.

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

17 PARTNERSHIPS FOR THE GOALS

Where:
Nordic

Inhalation technique – does it matter?

Project scope

The scope of this project was to increase awareness around the importance of correct inhalation techniques through a campaign, a webinar and a meeting for user representants. The project was a collaboration with the Norwegian Asthma and Allergy association.

The need

Many people living with lung disease are not aware that correct inhalation technique is an issue. Unfortunately, only a minority of users, 34%, can manage their inhalers correctly[2]. Still, they outperform HCPs: only 15.4% of HCPs have the know-how[3]. This is a major bump on the road to the well-treated patient. Also, the interchangeability at pharmacies in Norway leads to further risks of patients doing major mistakes when taking their medicine.

How can we help?

Awareness campaign on inhalation technique in relation to World Asthma Day (May 2, 2023). One-pager (3 versions) with a catchy illustration/picture and one simple message was posted on social media and printed and distributed through local NAAF affiliates.
QR code linked to NAAF`s homepage for detailed information on the importance of inhalation technique.

Social value

- Improve access to health promoting information.
- Contribute to medication adherence.
- Contribute to improved asthma control.
- Improve quality of life for people living with asthma

Where:
Norway

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[2] Sulku J. et al., Primary Care Respiratory Medicine 2021;31:5

[3] Plaza et al; J Allergy Clin Immunol Pract 2018;6:987-95

Awareness meetings for people living with lung disease

Background

Insights from advisory boards and meetings with people living with chronic lung disease highlight an urgent need to raise awareness around Chronic Obstructive Pulmonary Disease (COPD), both among HCPs and those affected.

The need

We see a particular need for improving the way chronic lung diseases are recognized and treated. Also, we acknowledge that the opportunity to meet and exchange experiences with others in similar situations is highly valued.

How can we help?

In collaboration with LHL (Norwegian patient advocacy group), we arranged three we-meetings for people living with chronic lung disease with the focus on awareness around COPD – symptoms.

Lungekafè in Steinkjer

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

Social value

- Disease awareness
- Opportunity for exchange
- Reduce stigma
- Empower people towards well-controlled disease and higher quality of life.

Where:
Norway

COPD report Sweden

Background

Chronic obstructive pulmonary disease (COPD) is the third most common cause of death worldwide, causing 3.23 million deaths in 2019[4]. In Sweden, COPD remains underdiagnosed, leaving many with no or insufficient treatment of their condition with potentially fatal consequences. It is estimated that 400-700 000 persons are living with COPD, leading to nearly 3000 deaths per year[5].

KOL RAPPORTEN 2023

En bortglömd folksjukdom

Riksförbundet HjärtLung

hjart-lung.se

How can we help?

A report on current issues with living with COPD in Sweden was compiled, aiming to raise disease awareness in the public as well as politicians and societal decision-makers. This was a collaboration between the patient association Riksförbundet HjärtLung (RHL), Chiesi and AstraZeneca.

Outcomes

The report and derived public communications include:

- Insights on patients experiences with COPD health care
- Expert interviews with health care providers
- Information on COPD, causes, treatment, and impact on quality of life and autonomy and health care costs.
- Identifying shortcomings in COPD care and key areas for improving healthcare
- Publicity in national and regional media
- Seminar in the Swedish Parliament

Social value

- De-stigmatizing a common disease
- Improved care for undiagnosed
- Better health and higher quality of life
- Lower societal costs due to no or poor treatment of COPD and the derived risks and costs for acute exacerbations (including hospitalization)

3 GOOD HEALTH AND WELL-BEING

Where:
Sweden

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[4] WHO fact sheet March 2023

[5] Socialstyrelsen, Nationella riktlinjer, Vård vid astma och KOL, utvärdering 2018

The “lifehack” flyer – for those living with COPD

Background

From a patient advisory board in 2022, we identified that a large group of people living with the chronic lung disease COPD – and their general practitioners – lack understanding of the paramount impact COPD has on life in general and knowledge about ways to preserve lung health and prevent worsening of disease.

The need

Knowledge can empower people living with COPD to gain control of their disease and to take actions to stay as healthy as possible. This project aims to increase access to information that will increase understanding of COPD and empower patients to manage their condition and to know when to seek help.

How can we help?

By collecting patient insights and identifying knowledge gaps, these points can be addressed in lay language in a flyer format that can be distributed in the doctor’s office or at the pharmacy.

Social value

- Improve understanding of COPD among newly diagnosed as well as those with a longer history with the disease.
- Facilitate dialogue between the doctor and those living with COPD
- Improved knowledge and understanding of COPD will help the individual to manage their condition better and to seek solutions that work *for them*.
- Increased awareness of our commitment to improving the lives of patients beyond pharmaceutical therapy.
- Facilitate the path to find the individualized treatment that, as far as possible, leads to a well-controlled disease.

3 GOOD HEALTH AND WELL-BEING

10 REDUCED INEQUALITIES

Where:
Denmark

COPD awareness – webpage for patients

Background

People living with Chronic Obstructive Pulmonary Disease COPD – and their doctors– lack knowledge about available treatments and understanding of the paramount impact COPD has on life in general. Persons living with COPD want access to both oral and written information.

The need

Knowledge can empower people living with COPD to gain control of their disease. This project aims to increase access to information that can improve self-management.

How can we help?

In collaboration with Lungeforeningen (patient advocacy group), AstraZeneca and Molecules, we are supporting the generation of a new COPD awareness web targeted for people living with COPD at all disease stages. High-quality articles, written by well-reputed pulmonologist Peter Lange will improve access to information for patients in plain language.

Social value

- Better understanding of COPD among diagnosed and relatives.

17 PARTNERSHIPS FOR THE GOALS

Where:
Denmark

How shared value makes us better

Shared value model

We believe that it is possible to do business in a conscious way that both benefits the community while also giving us a competitive advantage by generating insights about the patient populations that we seek to help.

Disease awareness

Lack of awareness about the disease might contribute to a delay of getting a diagnosis, and subsequently also receiving appropriate treatment for a treatable disease. We aim to enable patients that would benefit from our products to get equal opportunity for treatment.

Inhalation technique

Inhalation technique is a very important aspect that may contribute to suboptimal effect of an inhaled drug. There are a multitude of different inhalers which all have their unique technique, sometimes making things more complicated than necessary for the patient and leading to lack of efficacy. Improving the know-how to use our inhalers may contribute to more optimal use of our drugs, which is likely to increase the satisfaction with the products we supply.

Employee satisfaction

Having a sense of purpose drives our actions and impacts how we feel. The strive to make a difference in the world adds meaning and a sense of purpose to our work, positively impacting attitudes and work performance. For many of us, this is a strong personal value, making us proud to be a part of a shared value organization.

Stronger together

By establishing good relationships with external stakeholders, we believe it will help find more ways to contribute to more health. We strive for transparency in our relationships, showcasing our values and building trust as a partner for more health.

Success, for us, is making a positive imprint on the world.

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