

Book of good practice



GOOD PRACTICE NR 1 RUN FOR NEW LIFE

A social campaign with a nationwide dimension: Held twice a year in the format of a recreational Nordic walking relay march with the participation of transplant patients, well-known people from the world of film, theatre, stage, sport and the media, secondary school students and representatives of companies and organisations involved in the promotion of donation and transplantation. The campaign has been running since 2011.



SHORT DESCRIPTION

GOOD PRACTICE OBJECTIVES:

The aim of the campaign is, through broad media coverage, to educate and promote the idea of organ, haematopoietic cell and tissue transplantation and to activate the public for donation and transplantation from living donors. The campaign builds and strengthens public awareness by showing the importance of testimonies of will and talking to relatives about the decision to allow our organs to give someone a second life after death. The most important subjects of the campaign are transplant patients, who show healthy people that it is possible to return to a normal life and fitness after transplantation. Their touching and sometimes dramatic stories build the most important message of good practice is giving a space for thought to all those who have not yet made or are hesitating to make a donation decision.





the European Union

HOW IT WORKS/WHAT HAPPENED:

The campaign has been running for 13 years, till today 22 Run for New Life events organised, with two editions of the event always held in two cities each year: Wisła in the south of the country and the capital Warsaw. The name of the campaign refers to new life through transplantation. The formula of the campaign is constant - it is a relay nordic walking march in which the first shift is started by an authority in transplant medicine and related fields: transplant coordination, cardiology, nephrology, haematology, haematology, ophthalmology, or a well-known person from the world of film, theatre, music, stage, or sport; the "second shift" is a transplant patient; the "third shift" is made up of representatives of the media or social partners and organisations; the "fourth shift" is made up of secondary school students. The composition of the relay teams is not coincidental, the team of four is a coherent message: each group, whether it be well-known people from the world of broadly defined culture and the media, or partners, or finally young people meeting transplant recipients at the start line and learning about their stories, becomes an "ambassador" and "transmitter" of important ideas, and strengthens social awareness. It works to promote donation and transplantation not only in its environment. Added to this is the legitimisation of the campaign through the participation of medical authorities. The distance of the relay is symbolic and recreational; each person in the relay has to walk 1 km with poles. The route is always routed to allow the public to cheer on the starters, while giving free access to the testimonies of will stands.



An additional element of the campaign is the Second Life Galas of Polish transplantology, which have been organized since 2015. These are events during which individuals and institutions of particular merit to this field of medicine, whether in practice, medically and scientifically, or promotionally, receive Second Life awards. The awards are given in six categories: personality of Polish transplantology, active after transplantation / in this category people after transplantation are honored/, active for transplantation / in this category people who promote the idea of organ donation and transplantation are awarded/, media about transplantation, year in Polish transplantation. A special prize of the Run for New Life is also awarded, which goes to partners and donors working for Polish transplantation. Since 2015, 27 individuals and 29 institutions - medical institutions, companies, local governments and media - have received the Second Life awards.





BENEFICIARIES

WHO BENEFITS:

The whole of society without distinction by age, group or social status.





RESULTS FROM IMPLEMENTATION

• Since 2011, more than 4170 people have taken part in the campaign, marching more than 3770 kilometers together, more than 400 celebrities from the world of film, theater, television, sports, music and media, and more than 240 transplant patients. At the start of the Run for New Life since 2011, 1,272 three-person /since the 22nd edition, four-person/ relay teams have stood. 105 media, editorial offices, TV and radio programs have fielded teams in the event. Also 55 cultural institutions, sports associations, universities, high schools, foundations and associations joined the campaign.

• Media coverage plays a decisive role in the campaign. It generates public outreach. Since 2017, 11,531 publications have appeared on the Run for New Life, which generated 340,388,952 potential brand contacts, according to media research institutes. Only one edition of the Run for a New Life, which took place in May 2023, generated an outreach of 52,366,439 potential brand contacts which is a record value for a single event.





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• An effective campaign with great social impact, whose distinguishing feature from other such activities is that it communicates good news and talks about an important topic in a sympathetic way and with a smile in a friendly, open atmosphere.

• The power of good practice by bringing together people from different social and professional groups around the idea and setting one common goal.

• The choice of a simple form of recreation for everyone - a Nordic walking march showing that it is possible to live a normal life after transplantation and return to physical activity.

• Inviting the media of various communication platforms to act out of the ordinary, put up their relay teams in the Run for New Life on the one hand, and doing normal journalistic work on the other.

• Convincing the media that it is possible to work together and across divides promoting a socially important idea, and dispensing with rivalries, political contexts and marketing restrictions.

• Activation of transplanted people, who are often professionally and socially excluded.

• The compactness of good practice, which does not stretch time - in just three hours a great deal happens, a great many interesting people from different backgrounds are available to the media, which gives the opportunity for diverse and strong cover





DON'T WAIT, BECOME A DONOR /public campaign/

PARTNER: Slovenija-transplant COUNTRY: Slovenia

GOOD PRACTICE



GOOD PRACTICE NO 2 Don't wait, become a donor

A public campaign on a national level: billboards, media reports, radio shows, landing web-page (three weeks in January 2017).

www.daruj.si	
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postani darovalec.	
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Krótki opis

GOALS OF GOOD PRACTICE:

The aim of the awareness raising campaign was to put attention to the importance of organ donation and to encourage people to declare as donors. The idea was built around the concept of time and waiting: today, we are becoming more and more impatience. We struggle with seconds or minutes, when we wait for the bus, train, on a traffic light, in the cue and similar. On the other hand, patients on a waiting list for transplantation, need to wait for a suitable organ for days, weeks, months, even years. Some even die before getting a suitable organ for transplantation treatment.

The campaign was the result of the cooperation between Slovenija-transplant institute and media agency AV Studio. See the overview of the campaign and material presentation (in Slovenian): https://www.youtube.com/watch?v=FjlspJ6fQ4g.



Co-funded by the European Union



HOW DOES IT WORK/WHAT HAPPEND:

Posters were presented in places, when we usually need to wait: on a train station, on bus stations, in the waiting rooms in the healthcare centres and similar public spaces. The public was addresses with diverse questions: Are you tired of waiting for a train? Are you tired of waiting for the summer? Miha needed to wait for a heart more than 170 daysAfter, people were encouraged to reflect on the issue of organ donation, and invited to visit webpage for more information. A webpage www.daruj.si was designed for the purpose of the campaign. It presented emotional stories of people after transplantation, key explanations, statistics, and live map of locations for enrolment in the national register of designated persons. The authentic data and real patients' stories were used.

Simultaneous with posters on a public spaces, the national radio stations supported the action for a week, broadcasting daily the interviews with experts, patient stories, donor families etc. The final message of the campaign was, don't wait, become an organ donor. Give life a chance.

Many public and commercial media and other companies supported the campaign for free. Either in the form of spreading the message on the importance of organ donation, or preloading a landing page on their personal webpages. Several public figures acted as ambassadors of the campaign (sports man Primož Roglič, actor Saša Pavček, singer Trkaj).



BENEFICIARIES

WHO BENEFITED:

The target group was the widest general public.

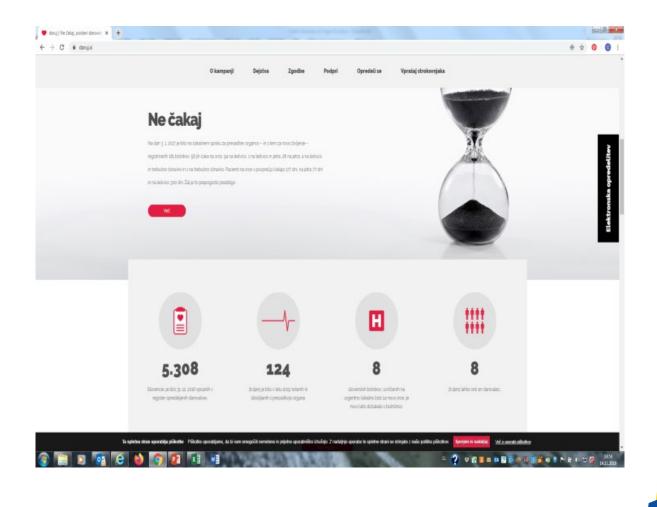
RESULTS FROM IMPLEMENTATION

• During the campaign in January 2017, many media coverages and talks were dedicated to the topic of organ donation. National radio broadcasted short interviews with experts, patients, families of the deceased donors everyday, in mornings and afternoons for a week (over 70 posts on TV, radio, newspapers and magazines)

• 15.000 visits to www.daruj.si web page were recorded in two months.

• All the efforts resulted in the increase of enrolment number in the national register for 500 % (in comparison to the same period year before). The general level of public awareness also increased, but we did not evaluate the effects.

• The campaign gained several awards in the media sector (media agency AV studio).





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• High-quality campaign that are for the good cause can be supported by the media and companies for free.

• National TV and radio stations are usually obliged to dedicate a portion of their programme to awareness raising campaigns or voluntary actions. Many times they are interested in the promotion of organ donation. Check if the situation is the same in your country.

• The development of the action and its content must run in close cooperation between the agency and professional body (medical experts, and others).

• Well-coordinated action with many partners operating on different levels (media houses, non-profit organisations, companies ...) yields better results.





Debate on Polish transplantology

/campaign using Poland's largest online medium/

PARTNER: Fundacja Pasjonaci Życia COUNTRY: Polska

GOOD PRACTICE



GOOD PRACTICE NO 3 Debata o polskiej transplantologii

A campaign with a national dimension: debates prepared in the formula of a live TV program. Panel discussions on the problems and challenges facing Polish transplantology, discussions on how to use the image in promoting transplantation and organ donation. Prominent medical practitioners, transplant patients, transplant coordinators, well-known people from the world of broadly understood culture and sport, representatives of companies involved in supporting transplantation are invited to participate in the debates. Executed in 2020-2022 for the largest Polish horizontal portal Onet.pl



SHORT DESCRIPTION

GOOD PRACTICE OBJECTIVES:

The aim of the campaign is to raise public awareness of organ donation and transplantation through media messages using the opinion-forming portal Onet.pl. The partner was not chosen by chance - it is the oldest and largest Polish horizontal portal generating large coverage and significantly influencing public opinion. The message intended for the portal was developed in consultation with the editorial team and was aimed not only at comprehensive information, but above all at an exchange of views. For this reason, it was important to select guests in such a way that different, often opposing and controversial opinions could emerge during the discussion. Such a formula is always more interesting and inspiring for the potential viewer, which is followed by greater interest in the topic.





JHOW IT WORKS/WHAT HAPPENED:

The campaign was run from 2020 to 2022. Guests invited to the TV studio included, transplant doctors, but also representatives of the Ministry of Health and the Organisational and Coordination Centre for Transplantation Poltransplant, transplant coordinators from all over the country, well-known people from the world of culture and sport, as well as representatives of companies involved in supporting transplantation and people after transplantation. Three debates on Polish transplantology were prepared. Each programme consisted of 3 to 6 panel discussions. A total of 46 guests took part in the broadcasts, giving a total of more than 7.5 hours of live TV coverage on the Onet.pl homepage.

BENEFICIARIES

WHO BENEFITS :

The whole of society without distinction by age, group or social status.





RESULTS FROM IMPLEMENTATION

- More than 1,750,000 unique visitors to the broadcast
- More than 3. 500 000 views of the broadcast

• Increased public awareness of informed organ donation and transplantation through extensive media coverage.





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• A campaign in collaboration with an opinion-important medium in the online sector offers the opportunity to build a large reach and positive public perception.

• Even difficult topics, which include organ donation and transplantation, must be communicated in an interesting, sometimes debatable and controversial way, but always easy for the potential viewer to digest.

• A requirement of cooperation with a large and opinion-forming medium is to provide it with a technically refined and perfectly prepared television broadcast, there is a need to employ a professional production agency.

• The opportunity for well-known people to present their own opinions and achievements in a prestigious and popular medium is an undoubted advantage of good practice.





A HEART ON THE HAND /theatre play/

PARTNER: Slovenija-transplant & Mladinsko theatre

COUNTRY: Slovenia

GOOD PRACTICE



GOOD PRACTICE NO 4 THE HEART ON THE HAND

The heart on the hand, a theatre play (season 2014/2015, the Mladinsko theatre).

SHORT DESCRIPTION

GOALS OF GOOD PRACTICE:

The aim of the play was to realistically, and yet poetically portrait the process of organ donation and transplantation in the Slovenian context of solidarity, professionalism, hopes and loses. The originally written theatre play was focused on the unseen relationship between the family of the deceased donor and the recipient of the heart. The story was linear, leading from the death to the life. The goal of the emotionally intense play was to encourage the audience to enter the sphere and confront the organ donation on a deep and intimate human level.

HOW DOES IT WORK/WHAT HAPPEND:

The excellent play was designed by the screenwriter Draga Potočnjak, directed by Mare Bulc and performed in the Slovenian youth theatre, the Mladinsko theatre. The original scenario was designed in close cooperation with the experts in the field of organ donation, communication with the relatives of the deceased and others. Slovenija-transplant supported the artists with expert feeds. The aim of the artists was to describe and show the topic in a documentary style. Additional value was, one of the main actors had an organ transplantation (younger actor, Alida Bevk). In many public interviews she spoke about her experience with organ donation treatment.





Co-funded by the European Union

BENEFICIARIES

WHO BENEFITED:

Younger generations General public Artistic scene

RESULTS FROM IMPLEMENTATION

• Unfortunately, the play only ran for one season. Due to changes in the management of the theatre, an unexpected withdrawal of the play from the program happened. Slovenija transplant wanted to help them in expanding the strategy of how to keep the play on the program by inviting more young and other groups of people as well as with co-financing based on a specific task to educate different publics about donation.

• With the good media coverage about the play, public attention was put on the subject of organ donation. It contributed to raised awareness.

The theatre play contributed to better understanding of the culture of organ donation in the Slovenian public sphere.





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• Theatre is an excellent terrain for the talk about an organ donation: the artistic freedom opens ground to talk about the deep human experiences and dimensions of life and death.

• Theatre play can work as an awareness raising tool for youth, for schools.



Over coffee about transplantology

/media campaign/

PARTNER: Fundacja Pasjonaci Życia COUNTRY: Polska

GOOD PRACTICE



GOOD PRACTICE NO 5 OVER COFFE ABOUT TRANSPLANTOLOGY

A nationwide media campaign: a series of interviews prepared in the format of a live TV program. Talks about transplantology, its problems and successes, news in the field of transplantation medicine and related fields, discussions on ways to promote and build public support for transplantation. Prominent medical practitioners, scientists, transplant patients, transplant coordinators, well-known people from the world of broadly defined culture and sport, representatives of companies involved in supporting transplantation and media representatives are invited to participate in the programme. Implemented since 2018.

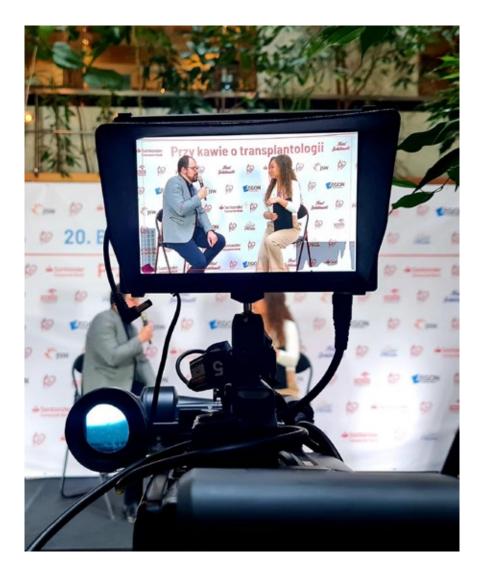




SHORT DESCRIPTION

GOOD PRACTICE OBJECTIVES:

The aim of the campaign is to raise public awareness about organ donation and transplantation through media messages using online channels and social media. In the Polish traditional media - television, radio and printed press - more and more material has been appearing in recent years about the need for donation and the effectiveness of transplantation, but this will never be 'first' information. The deliberate campaign 'Over coffee about transplantation', already with its non-accidental title suggesting that difficult topics will be brought closer to everyone in an accessible and understandable way. The campaign uses the most effective video format, building its reach through the use of the Internet and new media, and is focused towards reception on mobile devices.





HOW IT WORKS/WHAT HAPPENED:

The campaign has been running since 2018. Guests are invited to the TV studio mainly medical authorities - transplant doctors, nephrologists, cardiologists, hepatologists, ophthalmologists, haematologists - transplantology is treated broadly and comprehensively, and topics concerning organ transplantation, but also bone marrow, corneas or skin transplantation are discussed. Famous people from the world of culture and sport discuss with the hosts how to use their image to promote socially important topics. Representatives of companies discuss the need to get involved in important initiatives and treat them as part of corporate social responsibility, as well as acting from the heart and the possibilities of not translating these actions into marketing calculations. The media are looking for opportunities to better talk and write about transplantation between the big amount of daily news. So far, there have been five editions of the 'Over coffee about transplantology' - The broadcasts accompany the Run for New Life, a social initiative to support transplantology. Each programme consists of 15-25 interviews, totalling around 210 minutes of broadcasting. So far, the broadcasts have featured 106 guests, the transmission has been supplemented by 33 reporter interviews with transplant recipients. In total, this amounted to 17 hours of live TV coverage on the websites and social media of 22 national and regional media, including the internet portal of Poland's radio audience leader RMF FM, the leading news portal natemat.pl, the online edition of the daily Super Express, the medical portals Puls Medycyny and Termedia, and the transplantologia.info portal run by the Passionate Life Foundation, the only medium in Poland focused entirely to transplantation issues.

BENEFICIARIES

WHO BENEFITS:

The whole of society without distinction by age, group or social status.





RESULTS FROM IMPLEMENTATION

• More than 4 million recipients in total

• Increased public awareness of informed organ donation and transplantation through broad media coverage.





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• A campaign that is to have a high social impact must involve the media across different communication platforms.

• Only a comprehensive and qualitative approach to the topic of donation and transplantation guarantees media interest, which significantly influences the reach and effectiveness of the campaign.

- Only a high technical level of video transmission guarantees media interest in cooperation
- Building a base of media cooperating with the organiser of good practice becomes an important effect of the campaign.

• The interest of medical authorities in participating in the broadcast builds the position, image and credibility of the good practice organiser.





MY SCAR, MY LIFE

/photo exhibition artistic nude photos of persons
after transplantation/

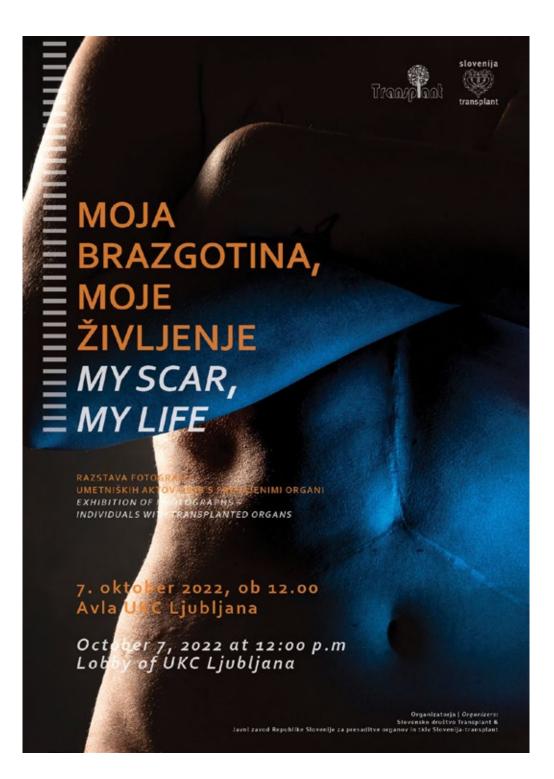
PARTNER: Slovenija-transplant & Patient association Transplant COUNTRY: Slovenia

GOOD PRACTICE



GOOD PRACTICE NO 6 MY SCAR, MY LIFE

An exhibition of artistic photo (nude) portraits of persons after transplantation & explanatory tests (2022-2023).



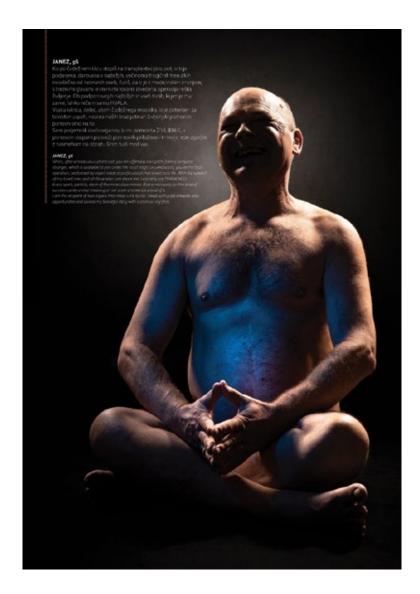


SHORT DESCRIPTION

GOALS OF GOOD PRACTICE:

The project is the result of cooperation of Slovenija-transplant and patient association Transplant. The initial idea was given by the patients after transplantation who wanted to publicly express a gratitude to the donors and break the tabus around organ donation and spread the message: declare as a donor. You have nothing to lose, while after death you might help another person, who needs organ transplantation.

For the effective communication, they revealed their bodies, their scarfs and intimate thought, what it means to have a second chance for life. 10 persons after transplantation cooperated in the project. Photographs were taken by Miran Juršič, the explanatory texts about organ donation, hints how to start a communication on organ donation, common myths and misconception and how to declare as a donors were provided by Slovenija-transplant.





HOW DOES IT WORK/WHAT HAPPEND:

Exhibition was solemnly open in University Medical Centre Ljubljana on the occasion of the European donation day on the 7th of October 2022. Exhibition is mobile, and is travelling to different locations in Slovenia. By now, it was presented in University Medical Centre Maribor, Public library Murska Sobota, and Healthcare centre Sevnica. Each opening is covered by the media reports (national and local), with the support of local professional community. A supporting event, frequent public talks, press conference and similar events are organized by the Slovenija-transplant Institute or Patient association Transplant. By now, the exhibition has been positively accepted by the public and has proven to be effective communication tool for organ donation.

BENEFICIARIES

WHO BENEFITED:

General public.

Professional public (in the donor hospitals, on a primary level of health care).

Media.

Patients after transplantation, patients on a waiting list.





RESULTS FROM IMPLEMENTATION

• Since the opening of the exhibition in October 2022, the rise in the number of declarations for organ donation can be observed. The rise is results of other communication actions, but the exhibition is one of most important ones.

- In 2022, the highest number of declarations was reported on a yearly level.
- With the exhibition, we are building the culture of organ donation and better trust in the system.
- The debates on organ donation are more frequent in the public sphere.





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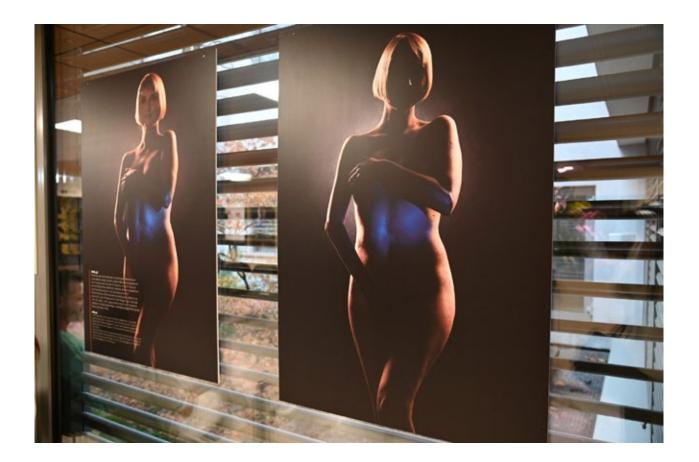
LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• Exhibition is an example of good practice for the cooperation between patient organisation and expert bodies. With knowledge and experiences, each adds an added value to the project.

• The exhibition can be excellently and efficiently presented in diverse settings: galleries, health care centres, libraries, ...

• Allow the photographer to express the artistic freedom.

• Exhibition opens the door for starting the talk on organ donations in diverse events and formats: round tables, concerts, TV shows, interviews, press conferences ... Form the events in cooperation with the local community/organizer.





Ordinary Card - Extraordinary gift

/social campaign/

PARTNER: Fundacja Pasjonaci Życia COUNTRY: Poland

GOOD PRACTICE



GOOD PRACTICE NO 7 Ordinary card – extraordinary gift

Social campaign with a national dimension: post-transplant people convincing people to have and handing out testimony of will- 200,000 plastic cards with individual consent for organ donation for transplantation after death. Implemented over two years /2018-2019/ during 60 major sports and cultural events in Poland.



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SHORT DESCRIPTION

GOOD PRACTICE OBJECTIVES:

The aim of the campaign is to build public awareness of informed donation and transplantation as the most effective treatment for organ failure. The way to do this is to encourage as many people as possible to have a donor declaration - a testimony of will. That they sign it, own it and talk to their relatives about it. Too few organs are still being transplanted in Poland. Many people do not have the chance to live to an operation, even though they could live a healthy life thanks to the procedure. Although the law in Poland allows organs to be taken from a death person who has not expressed their objection during their lifetime, doctors always talk to the family of the deceased and ask whether they have expressed such an objection verbally during their lifetime. Often, the family does not know what the will of the deceased loved one is, because there has never been a discussion about it. The idea of the campaign, in which the testimony of the will is decisive, is to help the family of the person who is waiting for a second life.





Krótki opis

HOW IT WORKS/WHAT HAPPENED:

The campaign took two years - in 2018 and the following year the project's premise did not change - in the second year it was expanded - cultural events were added to the sporting events. The organiser selected 30 events each year paying attention to the prestige, rank and number and social type of the audience. Depending on whether the events took place indoors - indoor volleyball and basketball competitions, theatre performances, stadiums, ski jumps or outdoors /running/, the testimony of will were placed on spectator seats with a parallel information campaign or added to the athletes' starting packages and distributed to the participants in parallel during the information campaign. Each certificate of intent in the form of a plastic card in ATM format was pasted into an information folder. In the folder, in addition to information on what a testimony of will is, how important it is and what its legal status is /in Poland it is not a document, but only an expression of will/, there were short statements by authorities in transplantation medicine encouraging people to have certificates of will, and in the second year variant short statements by transplant recipients were included in the folder. The front page included a reference to the words of the Holy Father John Paul II, who in 2000 emphasised that donating part of one's own body for the health of another person is an act of love, and such a decision has great ethical value.

Testimonies were handed out by transplant recipients - regional teams cooperating with the coordinator were created for this purpose - during meetings with transplant recipients, everyone attending the events was able to learn more about transplantation and, above all, find out that it is worth signing and carrying a will certificate.

In two years period, certificates of will went to, among others, fans and participants of the World Cup in ski jumping in Wisła, the finals of the Club World Championships in volleyball in Częstochowa, the Cracow Independence Run, the Champions League basketball match with Anwil Włocławek, the Hubert Jerzy Wagner Memorial in men's volleyball, the Kamila Skolimowska Athletics Memorial (now the Diamond League), the Enea IronMan triathlon in Gdynia, Olympic Picnic in Warsaw, football matches involving Widzew Łódź and Lechia Gdańsk /stadium in Łódź and Gdańsk/, the Silesia Marathon and theatre performances by the ROMA Musical Theatre in Warsaw.

Information about the campaign was provided by announcers before and during the event. Where possible, transplant recipients were 'included' in the opening programme of the event and presented by the presenters. They then had the opportunity to address the audience directly with information about the campaign.

In 2019, the campaign was reinforced by the insertion of 20,000 certificates of intent with an informative article in the full edition of the highly regarded and widely read magazine Esquire.





BENEFICIARIES

WHO BENEFITS:

The whole of society without distinction by age, group or social status.





RESULTS FROM IMPLEMENTATION

• During the campaign, 200,000 testimonies of will were handed over during 60 sporting and cultural events over two years - building public awareness.

• Transplant recipients participating in the transmission of certificates of intent were integrated and activated.

• Through non-standard media activities /information about the campaign provided in commentary by commentators of sports events during TV broadcasts, press and Internet announcements/ the public message about organ donation and transplantation was strengthened and expanded.





LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

• Effective campaign with high social impact at relatively low cost

• Activation of people after transplantation and, on the basis of their stories told at meetings, creation of broad public awareness.

• A different approach from the stereotypical campaign, naturally generating curiosity and media interest in good information with a positive message in a flood of "bad" news.

• Increasing public outreach through cooperation with a print medium selected for its ranges and content - insert testimonies of will.

 aunching cooperation mechanisms with various entities - public benefit organisations, cultural institutions, sports clubs, organisers of outdoor and indoor events, event agencies and local governments
 creating a large group of institutions supporting transplantation.





6-MINUTE WALKING TEST

PARTNER: Society for pulmonary hypertension of Slovenia COUNTRY: Slovenia

GOOD PRACTICE



GOOD PRACTICE NO 8 6-minute walking test

Pulmonary hypertension is rare disease. In cases of progression, the only treatment option is heart or lung transplantation. The aim of the association is to raise awareness about the disease and to prevent late treatment.

The video with adjusted 6-minute walking test is adjusted for healthy people: https://youtu.be/SduD-ErqRd8c

SHORT DESCRIPTION

The 6-minute walk test is a test that a doctor uses to monitor a patient with pulmonary hypertension. This test assesses how far the patient can walk in 6 minutes. And how he feels during the test.

HOW DOES IT WORK/WHAT HAPPEND?

We use this test in public awareness. But with one big difference. Everyone who takes the walking test is given a pinch on the nose and two straws in the mouth. Thus, it is only possible to breathe through straws, which is significantly more difficult. A patient with pulmonary hypertension already breathes like this when walking up the stairs, walking on a flat...

GOALS OF GOOD PRACTICE:

Experience shows that a tangible tool, such as the 6-minute walk test, really contributes to more successful public awareness. Healthy people can feel the symptoms of the disease on their own body.



BENEFICIARIES

WHO BENEFITED:

Healthy people at all ages, journalists (to write about), politicians (to listen to the needs of patients), all medical staff and patients' relatives (to better understand the disease).

With this tool, people who take this test remember the symptoms of the disease better.

We want journalists, famous people, and medical personnel to try the 6-minute walk test and feel the symptoms of the disease on their own bodies. We believe that this makes it easier for them to remember - the name and the symptoms of this disease.

In addition, the journalist is more likely to be attracted to this test because he can write an article from his experience and become more involved in the whole thing.

RESULTS FROM IMPLEMENTATION

In the video, you can see how surprised people are when they finish the 6-minute walking test. They didn't expect such heavy breathing. They saw that with so little air it is really very difficult to walk for so long, it is difficult to live. Some were frightened and stopped. There was a lot of empathy for the patients. Even the medical staff was surprised. Even if they know the disease, they are only now understanding patients with pulmonary hypertension.

LESSONS LEARNED / RECOMMENDATION FOR FURTHER USE OF THE GOOD PRACTICE

Invite even more people to this test, more journalists and family doctors, who are key in referring the patient to a specialist. Many family medicine doctors do not think about this rare disease and prescribe the symptoms to other, more common diseases such as asthma, bronchitis, COPD, even depression and lack of physical condition. On average, it takes 2 years for a diagnosis to be made and therapies to be instituted, if it is often too late for the patient.



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