



FORTEe

Get strong to fight childhood cancer: An exercise intervention for children and adolescents undergoing anti-cancer treatment

H2020 – 945153

D6.4 First patient and layman event

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Abbreviations

CAYA-C children, adolescents and young adults undergoing anti-cancer treatment.

IB Impact Board

PEx precision based exercise therapy

Executive Summary

The clinical FORTEe trial is a multi-centre, randomised controlled study that aims to evaluate the effect of precision based exercise therapy (PEX) in children, adolescents and young adults undergoing anti-cancer treatment (CAYA-C). The study participants will be randomly assigned to one of two groups: the experimental group (exercise group) receiving a PEX and a control group which receives usual care.

This deliverable is part of the work package 6 (WP6) “Dissemination, exploitation, knowledge Management” and as leader of the WP3 (Clinical trial), Fondazione MBBM was in charge of the deliverable “D6.4 First patient and layman event”.

The event was postponed, with the agreement of the EU officer, by 2 months. The first FORTEe Layman event was initially planned as an in-person meeting but the evolution of the pandemic did not allow us to stabilize the characteristics we would like to give to our event. The first patient and layman event finally took place the 28th of April 2022, in Monza (Italy) and 90 invitees joined it.

The idea is that the same format will be eventually replicated in all of the other centres of the FORTEe consortium, all over Europe.

The event invitees have been children, adolescents and young adult survivors of cancer, as well as their families. Local staff (medical doctors, exercise scientists, nurses, administrative personnel, volunteers) joined the event too. Finally, media representatives, sports testimonials, local and national authorities and supporters and sponsors joined the event too.

The MBBM families’ committee, Comitato Maria Letizia Verga, was in charge of the full organization of the event.

A welcome by Prof. Andrea Biondi, head of the Clinica Pediatrica Università degli studi di Milano Bicocca and by Giovanni Verga, president of the families’ committee Maria Letizia Verga was provided. A layman’s introduction of the FORTEe project was made by the Team Leader of MBBM, Prof. Adriana Balduzzi and by the Team Member Dr. Francesca Lanfranconi. The goals of the project and the methods have been presented with the attendants. The co-coordinator leader of the FORTEe project from Mainz, Dr. med. Marie Neu, joined this presentation. An in-vivo adapted training with guests and patients was run. Finally, a cocktail party permitted the invited people to informally share their thoughts about the FORTEe project.

A press release, summarizing the FORTEe goals and the Layman event with highlights of the event itself was shared with national and local media the day after.

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1 The 1st patient and laymen event – Deliverable report

The clinical FORTEe trial is a multi-centre, randomised controlled study that aims to evaluate the effect of precision based exercise therapy (PEX) in children, adolescents and young adults undergoing anti-cancer treatment (CAYA-C). The study participants will be randomly assigned to one of two groups: the experimental group (exercise group) receiving a PEX and a control group which receives usual care.

This deliverable is part of the work package 6 (WP6) “Dissemination, exploitation, knowledge Management” and as leader of the WP3 (Clinical trial), Fondazione MBBM was in charge of the deliverable “D6.4 First patient and layman event”.

A key aspect of FORTEe’s dissemination strategy and its communication goal is to make the project’s approach and methods, and eventually also its results and regulatory impact known to the general public and the young cancer patient community. At this stage of the project, our focus lies on making the project’s scope and approach known as widely as possible to the general public and to patients within Europe.

1.1 Planning and announcement of the event

The first patient & laymen event was planned in Monza in the Centro Maria Letizia Verga, department of the Clinica Pediatrica of the Università degli studi di Milano Bicocca where CAYA with haematological malignancies are taken care of. The partner MBBM organized the patient & laymen event, in collaboration with the families’ committee “**Comitato Maria Letizia Verga**”.

Due to the COVID-19 pandemic, the deadline of the first patient & layman event was postponed for two months to the **28th of April 2022**, to enable a safer meeting for all the participants (due to an enhancement of the pandemic situation).

The event invitees were **children, adolescents and young adult survivors of cancer**, as well as their **families**. Local staff (**medical doctors, exercise scientists, nurses, administrative personnel, volunteers**) were invited to join the event too. Finally, **media representatives, sports testimonials, local and national authorities and supporters and sponsors** joined the event.

The event was announced via the social media channels of MBBM, UMC-Mainz and FORTEe and through the FORTEe website. Due to the fact that the Layman event was run inside the hospital the number of invitees was limited to 90 participants and the following invite was emailed to selected invitees (see **Figure 1**).



Figure 1 Announcement of 1st patient and layman event by the Comitato Maria Letizia Verga.



Figure 2: The FORTEe Roll-Up poster, sent from the partner concentris, is put up by the MBBM and UMC-Mainz team for the event.

A plaque with FORTEe identifications is put on the wall near the gym’s entry door where FORTEe evaluations and training sessions will be run. The plaque was especially made for the Layman event occasion.



Figure 3: The FORTEe plaque near the gym's door.

1.2 Execution of the event

The 1st patient and laymen event was divided into 4 parts (see [Annex 1](#) for the detailed agenda).

A welcome by prof. Andrea Biondi, head of the Clinica Pediatrica Università degli studi di Milano Bicocca, and by Giovanni Verga, president of the families' committee Maria Letizia Verga, was provided. A layman's introduction of the FORTEe project was made by the Team Leader of MBBM, Prof. Adriana Balduzzi and by the Team Member Dr. Francesca Lanfranconi. The goals of the project and the methods have been presented to the attendants. As representative of the project coordinator UMC-Mainz, co- Dr. med. Marie Neu, joined this presentation.



Figure 4: Prof. Andrea Biondi, Dr. Carlo Mornati (Olympic rowing athlete and current Italian National Olympic Committee General Secretary), Mrs Raffaella Cucinotta (Comitato Maria Letizia Verga Communication team member), Dr. Momcilo Jankovic, Deborah Compagnoni (Olympic ski athlete and current Ambassador for the Olympic Winter Milano Cortina 2026).

An adapted training of Animal Flow, with guests and former patients was run. Animal Flow makes ground based movement, fun, challenging and effective. This system is designed to improve strength, power, flexibility, mobility, and coordination for all levels of fitness participants. An adapted version, especially thought for children with cancer, is used as part of the FORTEe training protocols.

Finally, a cocktail party permitted the invited people to informally share their thoughts about the FORTEe project.



Figure 5: Animal Flow adapted, training sessions with Sport Therapy athletes and guests of the Layman event.

2 Audience and number of attendees

The invitees were **2 children, 8 adolescents and 3 young adult survivors of cancer**, as well as their **12 families**. Local staff (**5 medical doctors, 15 exercise professionals, 2 nurses, 6 administrative personnel, 5 volunteers**) were invited to join the event too. Finally, **4 media representatives, 8 sports testimonials, 3 local and national authorities** and possible **20 supporters** and **12 sponsors** joined the event.

3 Feedback and impact

The event was enthusiastically well received by the audience. Many emails were received by the Comitato Maria Letizia Verga Comeettee the following days to thanks for the invitation and congratulated for the beautifulness of the FORTEe program. The Dean of the School of Medicine said:

“Good evening, thank you for organizing this very exciting as well as relevant human and scientific event. On behalf of the Department of Medicine and Surgery, heartfelt congratulations and best wishes for many more successes (daily and otherwise) go out to the entire Sport Therapy and FORTEe team.”

The 1st patient and laymen event was conducted and planned in a way, that the other recruiting centers/partners can translate it to their centers/institution. During the monthly Steering Committee of the FORTEe project, the highlights of the event will be discussed and an agenda of next possible Layman Event around Europe will be discussed.

A Media press was released during the week end 2 of the main local newspaper promoted the news (see [Annex 2](#)).

During the meeting, the FORTEe project was also heavily active on the **various social channels**. Especially on **Instagram**, who is most used by our target group, we could achieve a good outreach and see an increase of followers/likes during the 1st patient and laymen event.

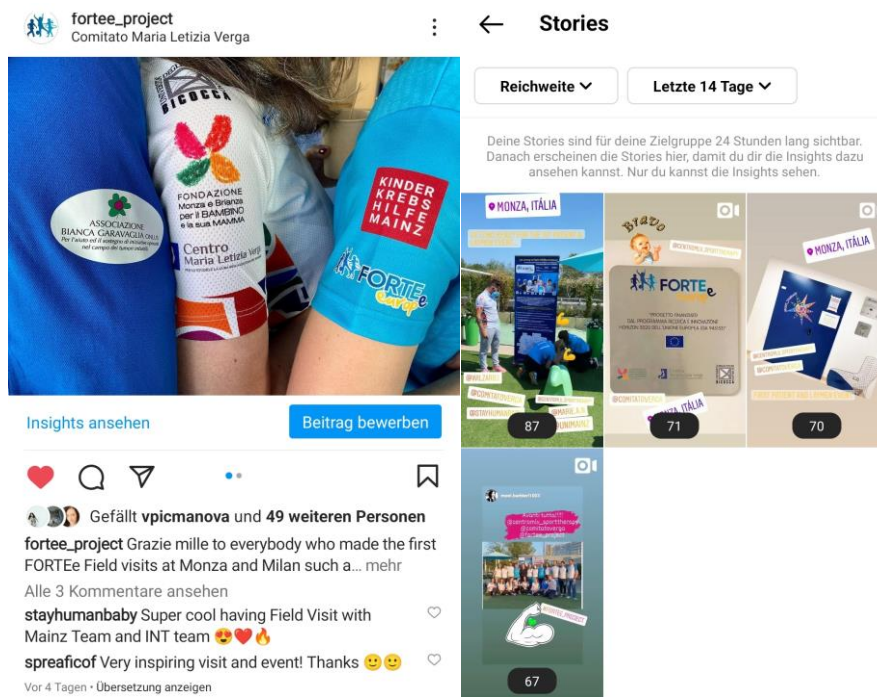


Figure 6: The Instagram social posts were well accepted by our followers (left side) and had a good reach (right side, see statistics of reach).

4 Conclusion

In conclusion, the FORTEe team, including the Impact Board (IB), is very satisfied with the interest, positive feedback, and overall outcome of the project’s 1st patient & layman event. The event set the stage for the second patient & layman event at the end of the 3rd project year (due by month 36), when first results and details about the clinical trials will be shared with the patient community.



Figure 7: MBBM, INT and Mainz team members.

5 Acknowledgement and Disclaimer

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 945153.

This report reflects only the author’s view and the Commission is not responsible for any use that may be made of the information it contains.

6 Annex 1

Layman event programme

PROGRAMME EVENT FORTEe April 28, 2022 at 17.00

Part 1 (25 minutes): Sport-therapy and FORTEe

- 17:15 - 17:20 Welcome and introduction Giovanni Verga and Prof. Biondi
- 17:20 -17:25 Prof.ssa Adriana Balduzzi (Sport Therapy project), Dr.ssa Francesca Lanfranconi (FORTEe project)
- 17:25-17:30: Dr. Momcilo Jankovic and Dr. Tommaso Moriggi present the Sport Therapy team.
- 17:30-17:35: Prof. Balduzzi introduces Mainz representative Dr. Marie Neu and Mainz team
- 17:35-17:40: Prof. Biondi introduces Prof.ssa Maura Massiminino and Dr. Filippo Spreafico

Part 2 (15 minutes): Sport champions

17:40- 17:55: Prof. Biondi calls:

- Deborah Compagnoni (Official Winter Olympics Ambassador of Milan Cortina 2026, multiple world and Olympic alpine skiing champion)
- Carlo Mornati (CONI secretary general, multiple world and Olympic rowing champion)
- Stefano Ghisolfi (current world champion of sport climbing)
- Michele Barbiero (mountain guide)

Part 3 (30 minutes): Animal flow session

- 17:55 -18:15 Dr. Lanfranconi and Tommaso Moriggi introduce the Animal Flow demonstration by Drs. Emanuele Villa and Valeria Valdata.

Round 1 Animal Flow adapted session with:

- VIPs guests (4)

Former Sport therapy athletes (4)

18:15 -18:35

2nd round Animal Flow session with:

- VIPs guests (4)

Former Sport therapy athletes (4) 18:15 -18:35

Part 4: 18:35 - 19:30 Refreshment - Wall challenge with the champions: Stefano Ghisolfi, Sara Grippo, Michele Barbiero, Massimiliano Gerosa

7 Annex 2

<https://www.ilcittadinomb.it/news/cronaca/monza-sport-therapy-diventa-un-protocollo-europeo-condiviso/#:~:text=Il%20progetto%20FORTEe%20si%20concluder%C3%A0,e%2C%20adolescenti%20e%20giovani%20adulti.>

Translation

Monza: Sport Therapy becomes a shared European protocol

The Sport Therapy project of the Maria Letizia Verga Committee of Monza, started five years ago, becomes a shared European protocol.

Sport, or rather Sport Therapy, has been at home at the Maria Letizia Verga Committee in Monza for five years. More than five hundred children, adolescents and young adults suffering from malignant hemopathy or undergoing bone marrow transplantation in this period have followed, supported by a team of professionals, specific training to maintain efficient lung, heart and muscles, the organs that are most affected by life-saving therapies.

Sport Therapy takes a quantum leap with a shared protocol

Now, however, this program takes a further leap forward. The doctors and researchers of the Monza facility will develop a protocol of exercises and activities for young and young patients with blood cancers that will be shared and made available to pediatric oncology centers distributed in Spain, Italy, Germany, England, France, Slovenia and Denmark, partners of the FORTEe research project, funded by the European Commission's Horizon 2020 research and innovation program (GA 945153) with 7 million euros.

Sport Therapy and the FORTEe project

The FORTEe project was officially presented on Thursday in the gym and on the terrace of the Center in via Cadore dedicated to this activity. Among others, Carlo Mornati, CONI secretary general and rowing Olympian, Stefano Ghisolfi, reigning world champion of sport climbing, and Deborah Compagnoni, great friend of Maria Letizia Verga and patroness of the event.

„Together with my cousins - said the alpine ski champion - twenty years ago I founded the association "Sciare per la vita" and I firmly believe that sport and physical activity represent a very important resource in everyone's life, for the benefits they can offer for our health and our well-being".

And the international research project FORTEe has precisely the objective of demonstrating that exercise and sport are a safe and potentially effective therapy to combat fatigue, maintain strength, aerobic capacity, coordination and agility and to counteract the problems related to disease and treatment in children and adolescents with cancer diseases.

Sport Therapy: precision training

The exercise and evaluation protocol will be developed from the experience and expertise of the Sport Therapy professionals at the Maria Letizia Verga Center. This protocol will define, first of all, when a child undergoing cancer therapy can start doing physical activity even during intensive phases of treatment. Subsequently, an evaluation will be carried out to verify the impact of the intervention performed. The final goal is to make the Sport Therapy intervention standardized throughout Europe and the world.

Today, in the center of Monza, from the moment of diagnosis, for each patient (from two and a half years old up to 18 years old) a precision training is defined, adapted according to the health conditions and the progress of the therapy, in constant contact and comparison with pediatricians.

Sport Therapy: the new Animal Flow and the future

Among the Sport Therapy practices used at the Maria Letizia Verga Center, a new feature is Animal Flow, a free-body workout that imitates the movements of animals and is inspired by disciplines such as yoga and dance. Very fluid movements are performed, which reproduce the 'gestures' of animals such as, for example, the gorilla that wakes up, the crab that moves its claws, and are also suitable for younger children to make the activity more fun.

The FORTEe project will end in August 2026. In addition to the Fondazione Monza e Brianza per il bambino e la sua mamma (Monza and Brianza Foundation for Children and their Mothers), the managing body of the Maria Letizia Verga Center, eight centers in which 450 children, adolescents and young adults will be trained are part of the European consortium. The Monza facility will be in charge of the clinical trials. In Monza, Adriana Balduzzi, pediatrician and head of the transplantation center, is directing the project, strongly desired and supported by Andrea Biondi, director of the Pediatric Clinic of the University of Milan Bicocca. Together with Verga, the other Italian center involved is the Istituto Nazionale dei Tumori of Milan, which participates in the project for the part of experimentation on pediatric solid tumors.

<https://www.mbnews.it/2022/04/sport-therapy-centro-maria-letizia-verga-monza/>

Translation

EXCELLENCE

Sport Therapy: Maria Letizia Verga Center of Monza, a model for Europe

Among the Sport Therapy practices used at the Maria Letizia Verga Center, a new feature is Animal Flow, a free-body workout designed by Mike Fitch that imitates the movements of animals.

Monza. It will be the doctors and researchers of the Maria Letizia Verga Center in Monza - thanks to their many years of experience in Sport Therapy activities - to develop a protocol of exercises and activities for children, adolescents and young adults with blood cancers that will be shared and made available to the pediatric oncology centers partners of the FORTEe research project, funded by the Horizon 2020 research and innovation program (GA 945153) and distributed in Spain, Italy, Germany, England, France, Slovenia and Denmark.

The definition of an assessment and intervention protocol is the first step of the international research project FORTEe that aims to demonstrate that physical exercise and sport are a safe and potentially effective therapy to combat fatigue, maintain strength, aerobic capacity, coordination and agility and to counteract the problems related to the disease and treatment in children and adolescents with oncological diseases.

Among the Sport Therapy practices used at the Maria Letizia Verga Center, a new feature is Animal Flow, a free-body workout designed by Mike Fitch that imitates the movements of animals and draws inspiration from disciplines such as yoga and dance. These are very fluid movements that reproduce the 'gestures' of animals such as, for example, the gorilla that wakes up, the crab that moves its claws, and are also suitable for younger children to make the activity more fun.

The definition of an assessment and intervention protocol is the first step of the international research project FORTEe that aims to demonstrate that physical exercise and sport are a safe and potentially effective therapy to combat fatigue, maintain strength, aerobic capacity, coordination and agility and to counteract the problems related to the disease and treatment in children and adolescents with cancer diseases.

The FORTEe project was officially presented yesterday, during an evening that involved doctors and researchers of the Maria Letizia Verga Center, the team of Sport Therapy professionals, young patients together with their families and all the supporters of the Committee. Well-known faces of sport attended the ceremony, which took place in the gym and on the terrace of the Center in Via Cadore in Monza, dedicated to this activity. Among them Carlo Mornati, CONI secretary general and rowing Olympian, Stefano Ghisolfi, reigning world champion of sport climbing.

Godmother of the event Deborah Compagnoni, alpine skiing champion, commented: "For me it is a great joy to be here today, together with the children, families and friends of the Committee Maria Letizia Verga that, together with the Association 'Sciare per la vita' I have the pleasure to support for many years with fundraising initiatives related to sport and movement. The project that the doctors and researchers of the Center have undertaken demonstrates a principle in which I firmly believe, namely that sport and physical activity are a very important resource in the lives of all, for the benefits they can offer to our health and our well-being".

The exercise and assessment protocol will be developed from the experience and expertise of the Sport Therapy professionals at the Maria Letizia Verga Center who have been involved in this activity for 5 years.

In the Center of Monza, from the moment of diagnosis, for each patient (from two and a half years old to 18 years old) is defined a precision training adapted according to the health conditions and the progress of therapy, in constant contact and comparison with pediatricians.

Francesca Lanfranconi, sports physician and researcher in human physiology at the Maria Letizia Verga Center adds, "The entire team of motor scientists and exercise professionals at the Center who work daily with our young patients have taken part in this project with great commitment, motivation and seriousness. We are honored to be able to make available the experience that we have gained from 2017 to date by 'training' over 500 boys and girls, adolescents and young adults suffering from malignant hemopathy or undergoing bone marrow transplantation so that they can benefit from training that aims to maintain efficient lung, heart and muscles, the organs that are most compromised by life-saving therapies."

Through the protocol will be defined, first of all, when a child undergoing cancer therapy can begin to do physical activity even in the intensive phases of treatment. Subsequently, an evaluation will be carried out to verify the impact of the intervention performed. The final goal is to make the Sport Therapy intervention standardized throughout Europe and worldwide.

The FORTEe project

FORTEe is an international multicenter scientific research project funded through the Horizon 2020 research and innovation fund of the European Commission with 7 million euros and that will end in August 2026, to which 16 institutions in 8 European countries have joined. In addition to Fondazione Monza e Brianza per il bambino e la sua mamma, 8 centers in which 450 children, adolescents and young adults will be trained are part of the European consortium: Region Hovedstaden, Copenhagen (Denmark), Universitätsklinikum Heidelberg (Germany), Univerzitetni Klinični Center Ljubljana (Slovenia), Universidad Europea de Madrid SAU (Spain), Centre de lutte contre le cancer Leon Berard Lyon (France), Oxford Brookes University (England), IRCSS Istituto Nazionale Tumori di Milano, coordinated by Universitätsmedizin der Johannes Gutenberg Mainz, Germany. The Mainz team was present at the event, with Marie Neu, pediatric oncologist, representing the coordinating center.

In addition to the clinical partners, there are also partners with expertise in motor sciences (Forma 3D Ltd, Ljubiana (Slovenia), Deutsche Sportshochschule Köln (Germany) and universitätsklinikum Essen (Germany), in digital technologies (Pixformance Sports GmbH, Berlin (Germany) and Nurogames GmbH, Köln (Germany), in administrative management of European projects (Concentris research management, Furstefeldbruck (Germany) and associations of patients and families who have experienced cancer at a young age (Fundatia Youth Cancer Europe, Cluj-Napoca (Romania)).

FORTEe is divided into seven work packages and Fondazione Monza e Brianza per il Bambino e la sua Mamma (MBBM), managing body of the Maria Letizia Verga Center, is leader of the work package dedicated to clinical trials. Directing the FORTEe research project is Adriana Balduzzi, pediatrician and

head of the transplant center. The project was strongly supported by Andrea Biondi, director of the Pediatric Clinic of the University of Milan Bicocca, which includes the Maria Letizia Verga Center,

The Center of Monza has been selected as leader of the clinical trial part of the project for its history of excellence in the treatment of young patients with leukemia, lymphoma and other non-oncological blood diseases and for the research project already underway on the impact of sport and precision exercise in patients. Another Italian center is the Istituto Nazionale dei Tumori of Milan, which is participating in the project for the part of the experimentation on pediatric solid tumors.