

PEER “Pediatric cancer patients and survivors Engaging in Exercise for Recovery”

Background

Approximately 1,500 Canadian children and youth under the age of 19 develop cancer each year. In Alberta, 160 kids will be diagnosed with cancer this year alone.

What follows are months of chemotherapy, radiation, immunotherapy, surgery, remissions and relapses as well as sleepless nights for both mom and dad. Some children who survive the disease may endure a lifetime of debilitating physical and cognitive problems—the side effects of cancer treatments. Most of them are affected emotionally.

Physical activity (PA) and sports are beneficial for healthy childhood development, improve academic achievement, and are essential for health maintenance and chronic disease management. These effects are amplified in children who face a chronic illness such as cancer.¹⁻⁴ The American Academy of Pediatrics recommends PA for many pediatric illnesses including pediatric cancer.⁵ Research shows that those who experienced quality PA during childhood and the development of physical literacy would be more likely to maintain lifelong active lifestyles.⁶ Therefore, PA is considered a right for every child as described in the United Nations Conventions on the Rights of the Child.⁷

Rationale

Fifty years ago, childhood cancer was an incurable disease. Today, almost 80% of children affected by cancer become long-term survivors. However, survival does not come without potential negative effects. Specifically, 62% of adult (mean age of 26.6 years) survivors of childhood cancer report having at least 1 chronic health condition, 27.5% of whom report a severe or life threatening condition.⁸ Therefore, diminishing the risk and severity of the adverse effects of cancer treatment is a therapeutic goal and PA has emerged as a promising intervention to meet this goal.⁹⁻¹¹

Cancer and its treatments have shown to affect a child’s capacity to be active from physical, physiological, and psychosocial perspectives.⁸⁻¹¹ Evidence shows that children with cancer are delayed in the development of physical literacy.¹⁶ There are several potential reasons that may explain this finding. First, cancer survivors may miss opportunities during normal development to learn how to jump, throw, or skip and gain confidence in these areas.^{12,15, 16} As a result, pediatric cancer survivors may feel uncomfortable playing sports or doing PA with their healthy peers. Another barrier is the lack of accessible programs, professional staff prepared to deal with special needs, and lack of information. Almost 25% of children who survive cancer do not perform PA at school.¹² To date, only a few community-based exercise programs have been described in the literature. Of these, none have been designed to be sustainable and available as programs for pediatric cancer survivors on an ongoing basis.¹³⁻¹⁵ For that reason there is an urgent need to provide children with cancer of all ages with a community-based exercise program.

Almost 80% of children affected by cancer become long-term survivors. However, 62% of adult survivors of childhood cancer at a mean age of 26.6 years, report having at least one chronic health condition.⁸ Therefore, diminishing the risk and severity of the adverse effects of pediatric cancer treatment is a therapeutic goal and emergent research shows that physical activity is an important intervention that can be implemented to meet this goal.⁹⁻¹¹ Cancer and its treatments have shown to affect a child's capacity to be active from physical, physiological, and psychosocial perspectives.⁸⁻¹¹

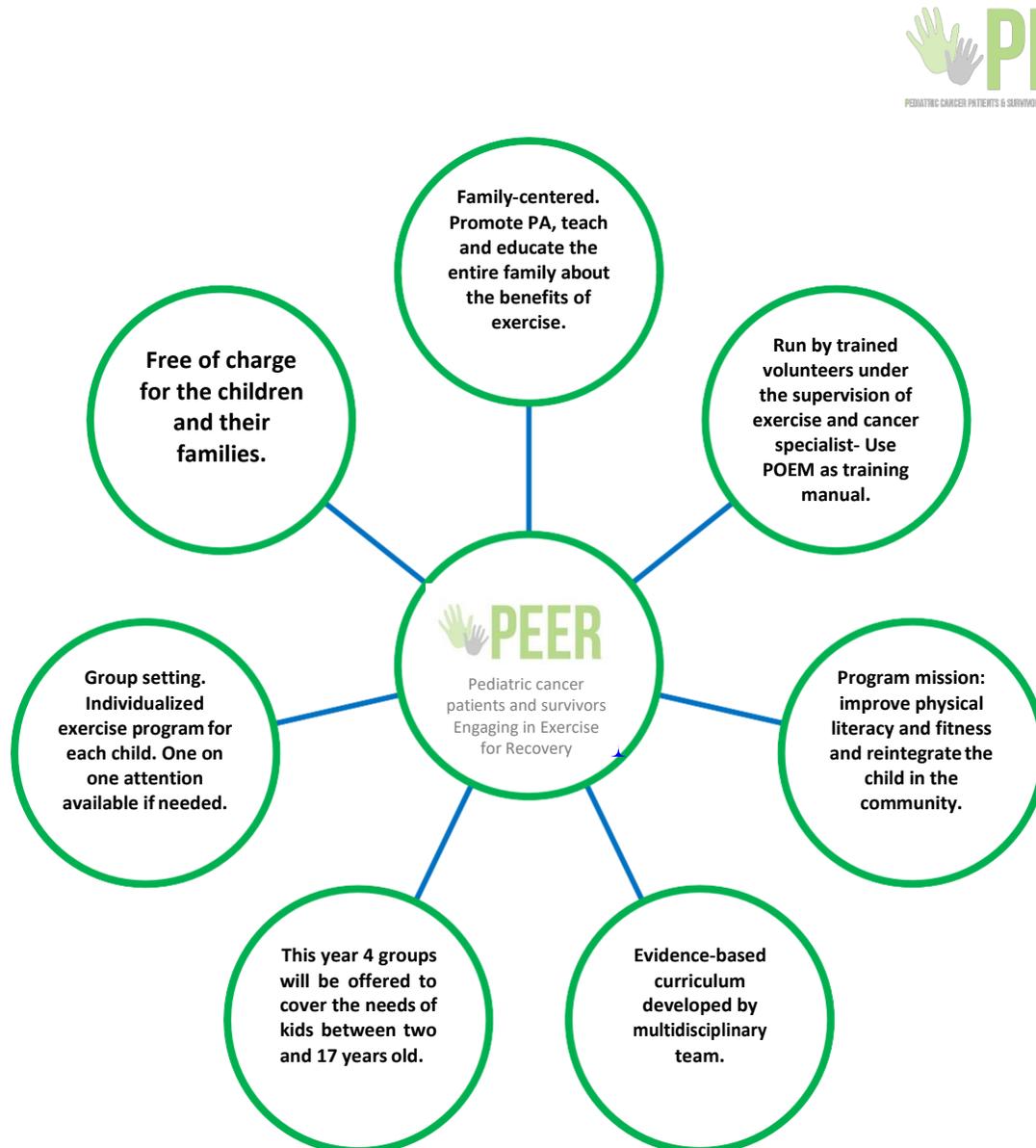
Also The American College of Sports Medicine Consensus Statement in Physical Activity Guidelines for cancer patients states: "Exercise training is safe during and after cancer treatments and result in improvement of physical function, quality of life and cancer- related fatigue in several cancer survivors groups. The Advice is to **AVOID INACTIVITY** even in cancer patients with existing disease or who are under intensive treatment.

Research shows a need to develop and implement targeted interventions that help childhood cancer patients to become more active and help them reintegrate into the

History and Development of the PEER Program

PEER stands for Pediatric cancer patients and survivors Engaging in Exercise for Recovery. The PEER program is an evidence-based exercise program developed five years ago in (2012) by the Health and Wellness Lab at the University of Calgary and approved by the Section of Hematology and Oncology at the Alberta Children's Hospital. PEER was developed by Drs. Carolina Chamorro Vina and supervised by Nicole Culos- Reed. The program is supported by an interdisciplinary team of pediatric oncology specialists from the Alberta Children's Hospital and aligns with contemporary evidence-based scientific research.

Figure 1. PEER program model



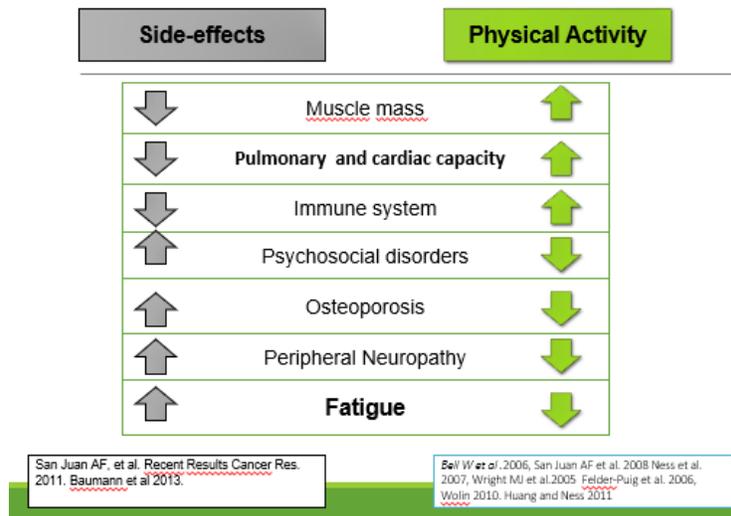
The program's model was presented in numerous scientific conferences and was awarded twice as:

- ✓ **Best poster in psychosocial field**, Pediatric Oncology Group of Ontario Symposium Nov 2012, Toronto. Chamorro Viña C et al.
- ✓ **Best poster in Healthy living and outcome management**, Alberta Children's Hospital Research Institute Symposium, April 2012, Calgary. Chamorro Viña C et al.

The model of the program was also published in 2016 in the **Rehabilitation Oncology Journal**, one of the worldwide lead scientific journals in pediatric cancer rehabilitation in order to increase awareness.

The **PEER program mandate** is to provide a fun, safe, tailored community-based exercise program that aims to diminish deconditioning, promote physical literacy, aid in the adoption of physical activity, and empower children and youth with cancer and their family to be physically active.

Program Goals



1. **Health**
2. **Physical Literacy:** The program is designed to build physical literacy in these kids who are either behind due to physical limitations or because they missed learning foundational skills in school when they were in the hospital for treatment.
3. **Normalcy:** We aim to bring normalcy in the life of children affected by cancer through a safe, clean and fun environment in which children with cancer can interact with their families and other peers.
4. **Quality of life:** Finally, but not of least importance, we aim to improve their quality of life.

PEER School Aged Children and Teen Program Curriculum

The program curriculum was developed in accordance with the Ontario curriculum, CSL4. The curriculum has three modules, and targets the following areas:

1. **Physical Literacy:** the development of fundamental movement skills and fundamental sport skills that permit a child to move confidently and with control, in a wide range of physical activity, rhythmic (dance) and sport situations. Physical literacy also includes the ability to “read” what is going on around them in an activity setting and react appropriately to those events.
2. **Healthy living:** students develop an understanding of the factors that contribute to healthy development, a sense of personal responsibility for lifelong health, and a respect for their own health in relation to others and the world around them. Key topics include Healthy Eating, Personal Safety and Injury Prevention.
3. **Active living:** students develop the skills and knowledge needed to participate regularly and safely in physical activity. It is important that the students develop and enhance their own current physical fitness and do so while enjoying it. Key topics: Active Participation and Physical Fitness

Developmentally appropriate curriculum has been developed to support the unique needs of the following age groups: (1) pre-school aged children; (2) elementary school-aged children; and (3) teens.

The PEER Preschool Curriculum

As stated in *FLIGHT: Alberta's Early Learning and Care Framework*, early childhood learning should be focused on broad holistic goals and knowledge.¹ The early childhood curriculum is created from children's interests and the recognition of the importance of participation of families and communities.

We know that children affected by cancer will be at higher risk of learning disabilities, decreased executive function, motor development delays, and may acquire sedentary behaviors. The PEER preschool curriculum integrates all of these factors into the program. These factors will be worked on at the PEER weekly sessions and families will be provided with information and activities to reinforce them at their home. Family participation is one of our main values because we know that family members work closely with their children on their development and therefore a family-centered approach was adopted in this curriculum.

The philosophy behind this curriculum also closely aligns with Alberta's early learning and care framework approach to early childhood education. We have created a balance between child-initiated learning through free play and following the child's interest while incorporating and exposing the children to fundamental movement skills and new energetic games. Through lesson plans and

intentional activities, we have incorporated development of executive function, and other developmental themes such as early literacy and numeracy. FLIGHT has also guided our image of the child to encourage strong relationship building between families and professionals, which has led to the co-construction of the curriculum and developing a place of vitality.

This PEER curriculum is valuable in ensuring the child's best interest. This includes supporting the children and families through changes. PEER curriculum aims to support cancer patients along their journey by providing families with support, various opportunities, and individualized sessions if needed. It is crucial to provide families with tools and information that allows them to keep their children active at PEER, throughout hospitalization periods and at home. PEER is taking the initiative to increase family awareness about the importance of exercise during cancer treatment and recovery. Throughout the curriculum, we encourage the use of different recreational facilities that will motivate families to stay active outside of PEER and understand the importance of these opportunities. PEER aims to provide any tools necessary to keep the family active at home and in the community.

Populations Served

The PEER program has been in partnership with the Kids Cancer Care Foundation of Alberta (Kids Cancer Care) since 2013. The number of program participants has been steadily increasing each year. When the program first started, we only had one group for all kids between 5 and 17 years old, and only 3 to 6 kids were in the program. Today, we offer 6 weekly classes in three different locations in Calgary (Alberta Children's Hospital, Wellsprings Randy O'Dell and Jamie's Preschool) and we also offer personal one on one sessions at the gym located in the Kids Cancer Care Office. Today more than 65 kids are part of the PEER program.

The program is available to children aged two to eighteen years impacted by a diagnosis of pediatric cancer, hematological disorder, or combined immunodeficiency disorder. Participants may participate in the program at any stage of their treatment journey and are required to submit a completed Physician Clearance Form, authorizing their participation in the program. They must also submit a detailed medical history, and list any of the child's interests, and identify parent/kid's objectives.

Program Delivery

All PEER program sessions are supervised by a CSEP-CEP or persons with pediatric cancer and exercise expertise. Sessions are facilitated by specialized volunteers, i.e. kinesiology, nursing and medical students, who receive mandatory training. All volunteers are required to complete 8 hours of online training offered by the Thrive Centre in which they learn about cancer and its treatments. Volunteers also complete 8 hours of in-person training in which they learn about four main areas: pediatric oncology epidemiology, treatment, side effects of cancer and its treatment, psychosocial issues in pediatric oncology, early childhood development, and how to modify exercise based on cancer side effects. These training sessions are facilitated by a multidisciplinary team of healthcare professionals led by Dr. Carolina Chamorro Vina. The team includes: Dr. Nicole Culos-Reed, PhD Professor of Health and Exercise Psychology in the Faculty of Kinesiology, and Professor in the Department of Oncology in the

Faculty of Medicine, University of Calgary; Dr. Gregory Guilcher, Pediatric Oncologist, Program Directors for Pediatric Oncology and Hematology, University of Calgary; and Dr. Fiona Schulte, Assistant Professor in the Department of Oncology, Division of Psychosocial Oncology in the Cumming School of Medicine at the University of Calgary, Psychologist in the Hematology Oncology and Transplant Program at the Alberta Children’s Hospital.

Activities are tailored to meet the unique needs of participants based on age and developmental stage. Whenever possible, participants are evaluated at the beginning and end of the PEER program to help establish benchmarks and indicators of success.

Program Locations

One-hour sessions are offered weekly at the Gordon Townsend Gym at the Alberta Children’s Hospital.

Sessions for three different age groups are offered every Wednesday night:

- Preschool group (2 to 5 years old) 5:00PM to 5:50PM
- School group (6 to 10 years old) 6:00 to 7:00PM
- Teens/Tweens (11 to 17 years old) 7:00PM to 8:00PM

In order to better serve the pediatric oncology and hematology population in Calgary, a South location (Wellspring Calgary) for the PEER program was opened in January 2019. Sessions for three different age group are offered every Monday night:

- Preschool group (2 to 5 years old) 5:00PM to 5:50PM
- School group (6 to 10 years old) 5:00 to 6:00PM
- Teens/Tweens (11 to 17 years old) 6:00PM to 7:00PM

Every Tuesday, PEER is offered at Jamie’s Preschool (Calgary location). Personal training sessions are offered to those children that present with more complex needs at the Kids Cancer Care Office -Gym.

In light of recent events regarding the novel coronavirus (COVID-19) pandemic, online program delivery is now available to the elementary school aged children and teens groups. Sessions are facilitated using an online platform, ZOOM, and led by Dr. Carolina Chamorro Vina.

Operating Budget

The following budget is a tentative summary of current program costs:

Supervisor		76,781.25
Training program facilitator costs		500.00

Participant snacks		900.00
Program supplies		2,800.00
Outreach Specialist		5,600.00
Overhead allocation		5,468.75
		92,050.00

Evaluation

Critical appraisal of the program's quality was done in June 2016. A parent survey was developed to determine families' satisfaction with the PEER program. Thirteen out of fifteen parents completed the survey. Findings indicated that 100% of survey participants agreed or strongly agreed that the PEER program met their expectations. Further, 100% of survey participants felt their children were safe at PEER, and 100% indicated that they would strongly recommend PEER to other families.

A survey of PEER participants showed that, before participation in the PEER program, the majority of participants did not meet the required level of daily physical activity as per established guidelines. However, survey results indicated that PEER made a huge difference in the lives of 40% of participants for whom PEER is the only physical activity they partake in on a weekly basis. In addition, 70% of parents reported that their child's ability to participate in sports improved with PEER. 100% of parents agreed that their child had the opportunity to experience new activities through PEER.

Anecdotes

Mother of a childhood cancer survivor: "My son has attended this program since he was four years old. attends this program since when he is 4years old. He is almost seven years old. I was not so worried about his physical activity but when he went to regular summer camp this summer...he really could not keep up with another healthy kids...He was completely exhausted and had so many bruises and bumps every day. PEER is very safe and fun for all of us. Thank you, Kids Cancer Care, Carolina, and all volunteers!"

Mother of a childhood cancer survivor (teen participant): "One morning my teenage daughter and I were late for the bus, so we started to run and for the first time in a long time, my daughter passed me and even beat me to the bus stop! I know PEER has increased my daughter's endurance and also her confidence. Now my daughter wants to walk to the bus stop for school instead of being driven".

Mother of a childhood cancer patient (teen participant) on active treatment: "I really enjoyed the talk and a chance to meet other parents! My son isn't feeling his best but we're really glad he could come tonight. He gets discouraged because skating is something that he used to be very good at but

he's lost so much muscle strength since starting chemo. He knows that the strength will return eventually. You have such a great group of people to help you out and we appreciate the time that you guys take with each kid! Thanks again for everything!"

Mother of a childhood cancer survivor (aged ten years) who started the program with very low self-confidence: "We want to say Thank you for great session yesterday! My son had a lot a lot of fun! He talked about this all evening yesterday and all morning today! He was very proud of himself! Thank you again for great opportunity!"

PEER volunteer and Registered Nurse on Unit 1 at the Alberta Children's Hospital: "I began volunteering with PEER because it is my passion to support children and families affected by cancer not only during at diagnosis, initial treatment, consolidation, and maintenance stages of their treatment, but also during equally as important stages and phases of their life. PEER is the perfect example of how a medical professional who supports these kids during some of the sickest and most fragile moments of their treatment can forget about those moments and play! Life after cancer is full of so much opportunity for these children and their families, yet I imagine and have heard through their anecdotes that it can be incredibly hard to navigate. Being a part of PEER has given me a beautiful perspective on what a family's life is like outside of the hospital walls for their children, and I believe has given me a valuable perspective on the holistic needs of these kiddos. It has absolutely made me a better oncology nurse, PEER gives me so much personal value and joy to be able to facilitate feelings of normalcy and most importantly fun for these kids and their families, in a safe space. So, thank-you so much for allowing me to be a part of this."

Program Summary

PEER is a community-based exercise program designed to improve recovery and enhance the quality of life for children affected by cancer, hematological disorder, and combined immunodeficiency disorders. The program aims to restore healthy levels of strength, aerobic capacity, flexibility, coordination, balance and physical literacy through exercises and games.

PEER provides the opportunity to re-introduce children and youth to their physical abilities and re-establish an active healthy lifestyle that impacts every aspect of their life. The significance of providing opportunities to regain health and activity levels for an under-served population is considerable. As more children are diagnosed with cancer, the need for creative and impactful out-of-hospital programming also increases.

Implications for Research

Because PEER was created as the post-doctoral project of Dr. Carolina Chamorro by the Health and Wellness Lab in the University of Calgary, PEER has a strong research background. In the past year, two graduate students chose PEER as the topic of their master's thesis. Both works improved the PEER program. Jena Shank developed an evaluation tool to applied in the PEER program and other community-based exercise programs.

1. Journal of Pediatric Oncology Nursing 2020;37(3):163-1791. Shank, J., Chamorro-Viña C., Guilcher G.M.T., Langelier, D. M., Schulte F., & Culos-Reed, S. N. Evaluation Tools for Physical Activity Programs for Childhood Cancer Survivors: A Scoping Review
https://prism.ucalgary.ca/bitstream/handle/1880/108737/ucalgary_2018_shank_jena.pdf?sequence=3

Dr. Chamorro Vina continues to conduct applied research and is working on the elaboration of a manuscript about barriers and facilitators of physical activity in teens affected by cancer. Dr. Chamorro Vina is also part of the iPOEG (International Pediatric Oncology Guidelines) that is working on developing a consensus statement and physical activity guidelines in pediatric oncology. Therefore, at least three scientific manuscripts will be published in scientific journals with national and international impact where PEER will be mentioned.

Future Directions

Future goals include: (i) provide participant under treatment from Southern Alberta (other than Calgary) with the opportunity to have online one-on-one PEER sessions that prepared them and their families to follow a home-based exercise prescription that will be given to them; (ii) improvement of parent programs (i.e. exercise opportunities for parents during school / teen PEER sessions); (iii) ongoing program evaluation; (iv) dissemination of the manual of operations and training manual to enable the expansion of the PEER program in Calgary and other cities.

- i. Establishing a home-based exercise program will allow us to access to pediatric cancer patients that are not able to come to the PEER group session. We might have kids that live outside Calgary or who are not able to come to group sessions due to severe immunosuppression. A home-based exercise intervention has to be created in a way that will motivate the kids to do it at home. As part of this intervention we need to create: (a) a research based exercise program based on individual's needs; (b) buy the equipment to do the program at home; (c) determine what variables will be measure to determine program's feasibility, effectiveness and safety; (d) a website is under development and an app may be developed to facilitate the execution of this program; (e) creation of a battery of test that allows us to measure the impact of the program in physical activity levels, physical literacy; health related fitness and quality of life; (f) create an appropriate mechanism to monitored the participant and adjust regularly their exercise plans.

Implementation of the home -based program has begun, with a number of participants that continue to attend the PEER program weekly. In May, a pilot PEER website will be created, and we will be gathering feedback to improve it. Meanwhile participants from outside Calgary who have temporarily relocated to the city to receive treatment will be scheduled for one on one exercise sessions so that they can continue to exercise at home. The program will be implemented in 2019.

Six fitness instructors were recruited, and they began facilitating exercise programs

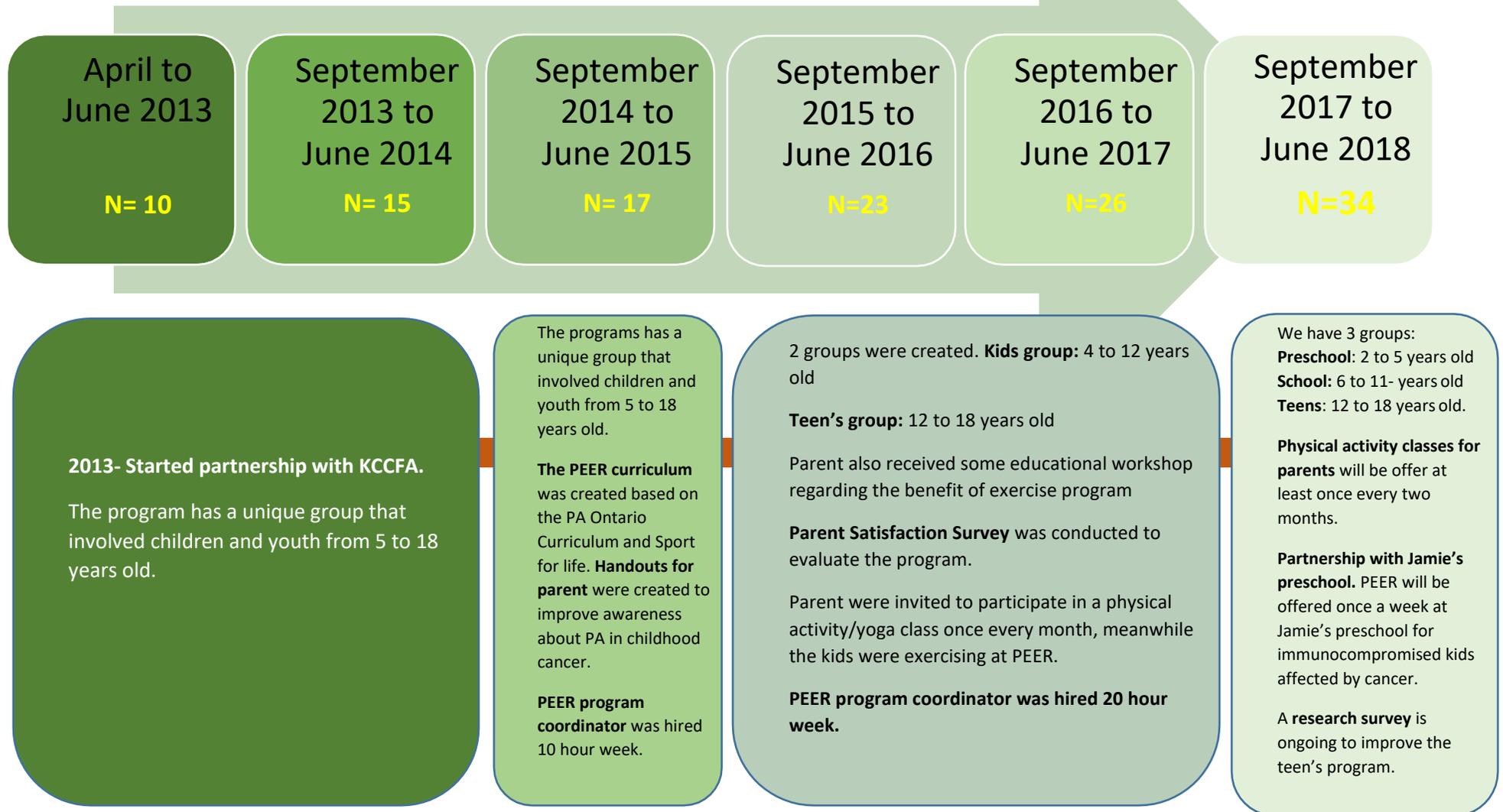
(i.e. Zumba, Pilates, yoga, dance and fitness) twice a month for parents of the PEER participants. Parents of each of the three age groups were able to join the exercise sessions while their children were participating in a PEER session. Unfortunately, this program was only implemented for two weeks before the novel coronavirus (COVID-19) pandemic evolved and the organization temporarily suspended all programs. Due to increase in the number of sessions offered at PEER, we need to re-evaluate how to best reach most of our parents at PEER. Exercise sessions for parents (e.g. yoga) are usually offered in the school-aged group. We need to develop a new plan and find resources to better serve all parent's aged group.

- ii. Need for ongoing program evaluation. As mentioned before Jena Shank developed an evaluation tool to fit the PEER program. This year we started to do a baseline evaluation for those participants who consented to the evaluation in October. However, due to the COVID –19, it won't be possible to do the post assessment. We will try again next year.
- iii. There has been international interest in the PEER program, and we have received a number of requests to disseminate program materials. We have been contacted by the following organizations:

Location	Organization
Irvin, California, USA	MaxLove Project http://www.maxloveproject.org/
Madrid, Spain	Cris cancer Foundation http://criscancer.org/en/
Bismarck, ND, USA	YMCA http://www.bismarckymca.org/
Leuven, Belgium	Leuven Hospital http://www.uzleuven.be/
Edmonton, Alberta, CA	Stollery Children's Hospital http://www.albertahealthservices.ca

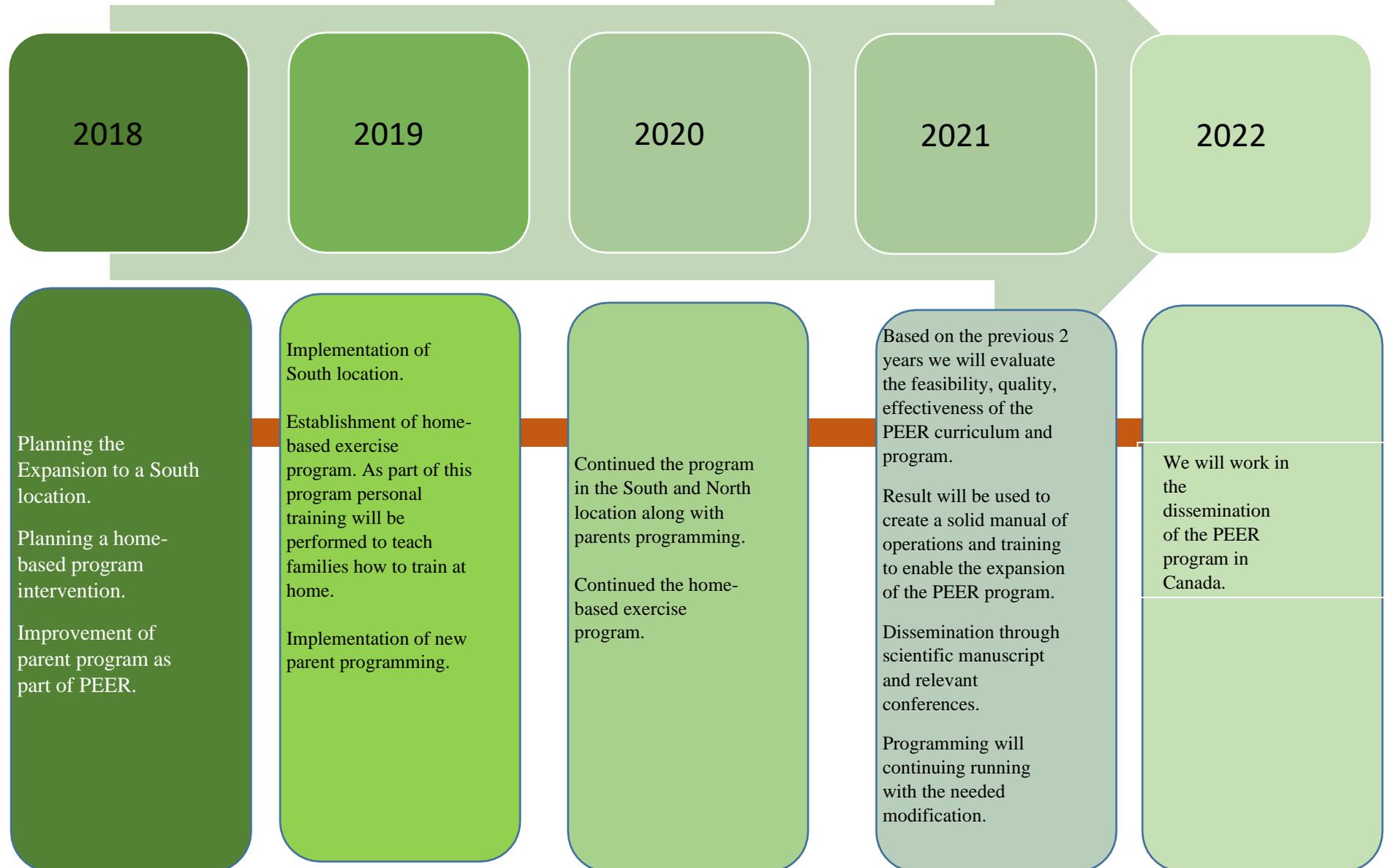
In the next year or two, we want to develop a strong user manual that will allow other institutions to reproduce the PEER model in other cities and countries. However, a lot has to be done in order to ensure that the established PEER standards are the same and that they are adapted to local needs.

PEER time evolution



KCCFA: Kids Cancer Care Foundation of Alberta; **N:** Number of participants registered in the program; **PEER:** Pediatric cancer patients and survivors Engaging in Exercise for Recovery; **PA:** Physical activity.

PEER 5-year plan



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