

CANCER  
GRAND  
CHALLENGES



Team:  
**NexTGen**

# NexTGen – Meet the Advocacy Panel

Cancer Grand Challenge – Developing  
next generation T cell therapies for  
children with solid tumours

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# Introduction

We are delighted to form the advocacy panel for NexTGen. We are looking forward to being an integral part of this unique global and multidisciplinary platform to help solve this complex challenge of treating solid tumours in children.

At the heart of NexTGen are patients, families and their stories. Each advocate brings their own experience and perspective of solid tumours whether a parent or a patient. We are all united in our passion and drive to enable research that leads to new scientific discoveries. Research that can lead to an improved prognosis with kinder and less toxic treatments. We will be a constant reminder of why we are all here, not just in the first year but in the years to follow. We will also ensure that the voice of the child/young person is not forgotten. They so often speak candidly about treatment and raise valuable points around quality of life.

In addition, we bring our own professional experience which can help shape our advocacy roles on NexTGen. The team has professionals who have worked in government affairs, law, marketing, banking, management of innovation projects and biotechnology. We will use these skillsets to contribute to delivering the objectives of the NexTGen involvement and engagement plan.

Finally, we all have different advocacy experience to share which will lead to idea generation, education and the continued evolution of the role patient advocates can play along the research pathway. It also allows access to worldwide advocacy networks across childhood solid tumour disease types, geographic locations and professional paediatric cancer bodies.

NexTGen provides a global platform for constant communication and collaboration between patient advocates and scientists and this will enhance our effectiveness.

We can't wait to get started!



# Sara Wakeling (UK)

Co-Founder and CEO, Alice's Arc

E: [sara.wakeling@alicesarc.org](mailto:sara.wakeling@alicesarc.org)

## Experience with solid tumours:

My eldest daughter, Alice, then aged three, was diagnosed with metastatic, fusion positive rhabdomyosarcoma, with the primary tumour attached to the submandibular gland in her neck. She spent almost five years battling the disease, relapsing twice, and enjoying two periods off-treatment, before dying on 8th October 2019, aged seven. Her treatment involved intensive chemotherapy, maintenance chemotherapy, relapse chemotherapy, radiation and surgery. It was led by Great Ormond Street Hospital, UK. She travelled to the U.S. for proton radiation on frontline treatment and to Amsterdam for AMORE (surgical resection, brachytherapy and surgical reconstruction) on first relapse.

## Advocacy experience:

- **Alice's Arc, Children's Cancer Charity** (November 2015-current). The charity aims to fund research into finding new, kinder treatments for rhabdomyosarcoma. It has experienced recent growth and has now raised over £2million with annual funds now in the region of £500K per annum. This growth is due to the creation of a network of family Arcs (at any stage of the illness trajectory) to help pool funds for meaningful, patient-led research, bring together a community of rhabdomyosarcoma families and offer a safe, support group for these families. The charity is now involved in funding/co-funding seven rhabdomyosarcoma research projects focussed on new treatments, new drugs, enhancing biological understanding, modelling, devising liquid biopsies to detect and predict disease and decision-making at the point of relapse.
- **A member of the European Paediatric Soft tissue sarcoma Study Group** (EpSSG) parent group (December 2020-current)
- **Consumer Member for the NCRI, Novel Agents Subgroup of the Children's Group** (March 2022-current)
- **PPI representative** on various research projects including; REFoRMS: aiming to understand decision-making processes where a child or young person has relapsed or refractory rhabdomyosarcoma and 'Image-guided surgery to improve precision and safety in removing solid paediatric cancers: from the bench to the operating theatre'.

## Professional skills:

- PPI/E Research Assistant at the Louis Dundas Centre for Children's Palliative Care at UCL GOS ICH (March 2020-current)
- Career in marketing, PR and account management within the professional services sector
- A Certificate of Higher Education in Counselling & Counselling Skills from Birkbeck College, London

## Goals for NexTGen:

- To contribute to the development and implementation of the clinical trials including; recruitment, design, communications and patient/family experience.
- To enhance the knowledge of the parent/patient community on next-generation CAR T-cell therapy treatment through meaningful engagement activities.
- To represent the community of parent/patient voices in the creation of next generation CAR T-cell therapy options for those children diagnosed with solid tumours.



# Gavin Lindberg (USA)

President & Co-founder of Evan's Victory Against Neuroblastoma Foundation (The EVAN Foundation)

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## Experience with solid tumours:

My son, Evan, passed away at the age of seven in 2010 after courageously battling stage IV, n-myc amplified neuroblastoma for four years. He was my only child. The relentless assault of neuroblastoma and the relentless brutality of Evan's treatment drives me to be an advocate for children with solid tumors. The status quo is completely unacceptable and kids like Evan should be the highest priority in cancer research.

## Advocacy experience:

- **The Evan Foundation** (2011-current). The Foundation supports children and families battling paediatric cancer through Patient Wellness, Education & Advocacy, and Research programs. Major initiatives include:
  - Providing college scholarships to high-risk pediatric cancer patients and survivors
  - Sponsoring "Treats & Treasures Carts" at children's hospitals across the U.S. and Canada that brighten the days of more than 1,000 young cancer patients a week
  - Advocating for increased resources for pediatric cancer at the federal and state level
  - Raising public awareness of the challenges of childhood cancer and serving as an educational resource for parents and families
  - Funding childhood cancer research, including a program dedicated to supporting talented early-career neuroblastoma investigators
- **Parent Advisory Council**, New Approaches to Neuroblastoma Therapy Consortium (2011-present)
- **Parent Advocate** representing the Children's Hospital of Philadelphia on the St. Baldrick's Foundation/Stand Up To Cancer Pediatric Dream Team (2018-present)
- **Parent Advocate** on the National Cancer Institute's Pediatric Immunotherapy Discovery & Development Network (2019-present)
- **Founding President** of the Band of Parents, a New York based neuroblastoma research organization (2007-2011)

## Professional skills:

- Prior to transitioning full-time to the EVAN Foundation in 2021, Gavin spent 25 years as a government affairs and patient advocacy professional in Washington, D.C. He has extensive policy and advocacy experience in the rare disease, academic health sciences, and biotechnology sectors, and service as an aide in the U.S. Congress and British House of Commons.

## Goals for NextGen:

- To be a voice for parents and patients within the team and serve as an educational resource for families interested in the promise of engineered T-cell therapy.
- To raise awareness of the work of the NextGen investigators within the childhood cancer lay community.
- To be an advocate for streamlined patient access to immunotherapy research and clinical trials.



# Abbe Pannucci (USA)

Patient Advocate

E: [abbepannucci@gmail.com](mailto:abbepannucci@gmail.com)

## Experience with solid tumours:

Abbe was diagnosed with stage 4 rhabdomyosarcoma at the age of ten in November 2010. Her doctors had found a large tumour in her pelvis that had spread to her hips. She received 52 rounds of chemotherapy at Children’s National Hospital in Washington, D.C. Abbe then underwent radiation therapy for eight weeks at the University of Maryland Medical Center in Baltimore. Abbe’s tumour was finally removed, and in 2012, she was declared cancer free. Abbe has been in remission ever since.

## Advocacy experience:

Abbe’s experience has inspired her involvement in patient advocacy and cancer awareness. In high school, Abbe organised and led a Relay For Life team consisting of her fellow students and teacher’s multiple years in a row. Her team raised money for the American Cancer Society whilst promoting cancer awareness in their community. Abbe currently volunteers on an advisory committee for the Adolescent and Young Adult Oncology Program at Children’s National Medical Center.

## Professional skills:

Abbe recently graduated from the Macaulay Honors College at The City College of New York with degrees in biotechnology and philosophy. Abbe’s passion for science has led her to work in multiple laboratories across NYC during college where she conducted virology, immunology, and parasitology research. Abbe now works as a laboratory technician at the UPMC Hillman Cancer Centre whilst preparing for graduate school.

## Goals for NexTGen:

- To advocate for the improvement of treatment options for children diagnosed with solid tumor cancers, specifically geared toward next-generation CAR-T-cell therapy.
- To contribute to the development and implementation of clinical trials for the NexTGen team.
- To participate in two-way mentorship with our doctors and scientists in order to better advocate for and educate the patient/parent community while simultaneously keeping up to date on the science being conducted by NexTGen.



# Patrick Sullivan (Canada)

Founder & President,  
Team Finn Foundation

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## Experience with solid tumours:

My twin son, Finn was diagnosed, aged 21 months, with rhabdomyosarcoma in 2007. Finn was treated using a combination of chemotherapy drugs (vincristine, actinomycin and cyclophosphamide), radiation and surgery. I heard the word incurable for the first time in May 2008, when the cancer returned. Finn died on 9th October 2008.

## Advocacy experience:

- **Team Finn Foundation** (2009-current): The foundation is dedicated to raising childhood cancer awareness and to raising funds for cutting edge paediatric cancer research. Since its inception it has raised over \$2million.
- In 2019, awarded the **Exceptional Leadership in Patient Involvement in Cancer Research** and the **Governor General's Medal for Volunteers**.
- **Co-founder** and **Past Chairman** of Ac2orn (Advocacy for Canadian Children Oncology Research Network)
- **Director** and **Past Chair** Childhood Cancer Canada
- **Co-founder** and **Past Chairman** of Ac2orn (Advocacy for Member of Executive of Terry Fox Research Profile Initiative)
- **Lead Advocate** on St Baldrick's/Stand Up To Cancer Immunogenomics Dream Team
- **Advocate** on SU2C Stem Cell Dream Team
- **Member** 3CTN Scientific Advisory Board
- **Director** Canadian Cancer Research Alliance
- **Member** of Arnie Charbonneau Cancer Institute External Advisory Board
- **Lawyer**
- **Father**

## Professional skills:

- Securities & Corporate, Commercial Litigator. Currently leads Whitelaw Twining's Securities Law Group. He previously spent just under 20 years as a partner at a small boutique litigation firm he helped found.

## Goals for NexTGen:

- To see Canadian kids get access to the clinical trials by streamlining international regulatory approval processes.
- To enhance access for kids worldwide to the clinical trials by using what we learn from the example of the Canadian kids.



# Patricia Blanc (France)

Founder & President, Imagine for Margo – children without cancer

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## Experience with solid tumours:

My daughter, Margo, died on the 7th June 2010 after a 16-month battle with a glioblastoma brain tumour. She was 14 years old. During her illness, she gathered 103K euros that were given to Gustave Roussy for research on her cancer.

## Advocacy experience:

- **Imagine for Margo** (2011 to current). The charity continues Margo's initiative by leading advocacy and fundraising to accelerate research in order to better understand and cure childhood cancer. Since inception 15 million euros and counting have been raised and 25 new treatments funded in innovative clinical trials.
- Patricia is highly active in **advocacy efforts engaging with French and European politicians**, regulators and the pharmaceutical industry to make laws and research more adaptable to facilitate better treatments for children with cancer. She was awarded a Vanity Fair award in 2016 as one of the 50 most influential French people in the world and the Chevalier de l'ordre National du Merite.
- **Member of the Scientific committee of the SFCE** (Société Française de lutte contre les cancers et leucémies des enfants et adolescents)
- **Member of the Scientific Council of Gustave Roussy, Villejuif**
- **Member of Childhood Cancer International-Europe** (research & innovation and public affairs committees)
- **Board Member of the ACCELERATE international platform** to develop new drugs for children
- **Member of the ITCC** (Innovative Therapies for Children with Cancer) advocacy committee
- **Member of the ITCC Brain tumor Group**
- **Member of the European Commission thematic group** on childhood cancer of the Cancer Stakeholder Contact Group
- **Member of the European Economic and Social Committee**

## Professional skills:

Patricia has twenty years' experience working in finance (project management, Chief Operation Officer, audit, human resources) in one of the largest banks in France. She worked in South Africa (3 years), Paris and New York City (7 years). She has devoted all her time to Imagine for Margo since it was created at the end of 2011.

## Goals for NextTGen:

- To bring my European experience on research and access to new drugs
- To help improve the design of the clinical trials
- To contribute to the development and implementation of clinical trials for the next-generation CAR T-cell therapy
- To enhance recruitment and access to clinical trials for children in Europe and worldwide



# Scott Crowther (UK)

Co-Founder, Pass The Smile for Ben (CCLG named fund)

E: [scott@thecrowthers.co.uk](mailto:scott@thecrowthers.co.uk)

## Experience with solid tumours:

Our son, Ben, was stolen by alveolar rhabdomyosarcoma in June 2019, age 7, just one year after being diagnosed. His treatment was led by Birmingham Children's Hospital, UK and involved the intensive chemotherapy IVADo protocol.

## Advocacy experience:

- **Pass the Smile for Ben** (2019-current). Our Children's Cancer and Leukaemia Group (CCLG) special named fund in memory of Ben has now raised £150,000 and co-funded four rhabdomyosarcoma research projects.
- **Member** of Paediatric Oncology Reference Team (PORT): focuses on reviewing paediatric oncology clinical trial documentation.
- **Member** of CCLG PPI research group: reviews funding applications and lay summaries received by CCLG. Provides strategic assistance on the CCLG Tissue Bank.
- **PPI representative** on various research projects including; REFoRMS: aiming to 'Understand Treatment Decision-Making Processes in Families where a Child or a Young Person has Relapsed or Refractory Rhabdomyosarcoma, Children's Cancer Priority Setting Partnerships (PSP): aiming to identify the Top 10 unanswered research questions according to patients, parents and clinicians and ENHANCE (End of Life care for infants, children and young people): a study aiming to increase understanding about the different ways end of life care is provided for children and young people in the UK.

## Professional skills:

Works as an Innovation Manager at University of Warwick, scoping and delivering collaborative Innovation projects with companies, including managing applications for government funding.

## Goals for NexTGen:

- To try to give the kids a voice and make sure they're not forgotten amongst all the science.
- To contribute to the research direction of the project and ensure it is effective and relevant.
- To help improve the collection, storage and use of tissue and other biological samples for research use.



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