

Manchester NF EURO 2022



EVENT PROGRAMME

EVENT AGENDA:



IN PERSON EVENT

OCTOBER 10-11, 2022

Central Manchester



Network: Conference
Password: Mercure24

IN PERSON EVENT

OCTOBER 10-11, 2022

Central Manchester



WELCOME MESSAGE

Welcome to the **20th European Neurofibromatosis Meeting Manchester UK** face to face conference. Whilst virtual conferences have led to a new way of working collaboratively internationally, these have somewhat stifled new collaborations as we have missed out on meeting socially together, as well as being able to talk face to face around posters. This is the 20th European Neurofibromatosis Conference representing over 30 years of NF conferences in Europe. The last conference was held in Rotterdam as a virtual conference in 2020 and previous conferences included the global Paris conference in 2018, the 2016 conference in Padua, 2014 in Barcelona with the 15th European NF meeting being held in Istanbul. This 2022 conference will be the second time that Manchester has hosted the European NF Conference. Manchester has a world-leading reputation in neurofibromatosis research and is one of just two highly specialised services for NF1 in England, as well as the lead centre for the four centres NF2 highly specialised service set up in 2010. NF research began in the late 1980s in Manchester, producing the first management consensus guidelines at Old Trafford in 2004. Manchester has a rich history of clinical, epidemiological and molecular research on NF1, NF2 and Schwannomatosis. We trust that the Manchester conference will be an opportunity to bring us all together again to foster new research collaborations and to update ourselves on the most advanced research on neurofibromatosis.

We give you a warm welcome to Manchester.

IN PERSON EVENT

OCTOBER 10-11, 2022

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ORGANISING COMMITTEE



Prof. Gareth Evans

Professor in Medical genetics and
Cancer Epidemiology, University of
Manchester, UK



Dr. Grace Vassallo

Consultant Paediatric Neurologist and
Clinical Lead HSS Complex NF1 Service,
Manchester University NHS Foundation
Trust



Mrs. Judith Eelloo

Lead Nurse HSS Complex NF1 Service,
Manchester University NHS Foundation
Trust

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SCIENTIFIC COMMITTEE



Prof. Gareth Evans



Dr. Shruti Garg



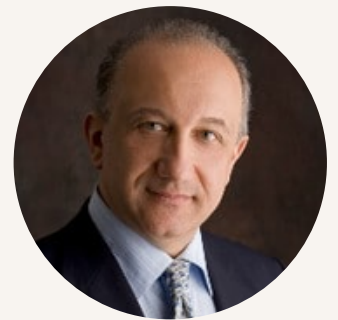
Prof. Stavros Stivaros



Prof. Rosalie Ferner



Prof. Scott Plotkin



Prof. Marco Giovannini



Prof. Michel Kalamarides



Prof. Juha Petonen



Prof. Eric Legius

IN PERSON EVENT

OCTOBER 10-11, 2022

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SCIENTIFIC COMMITTEE



Prof. Ian Kamaly



Dr. Emma Burkitt-Wright



Prof. Ignacio Blanco



Prof. Pierre Wolkenstein



Prof. J P Kilday



Dr. R. Oostenbrink



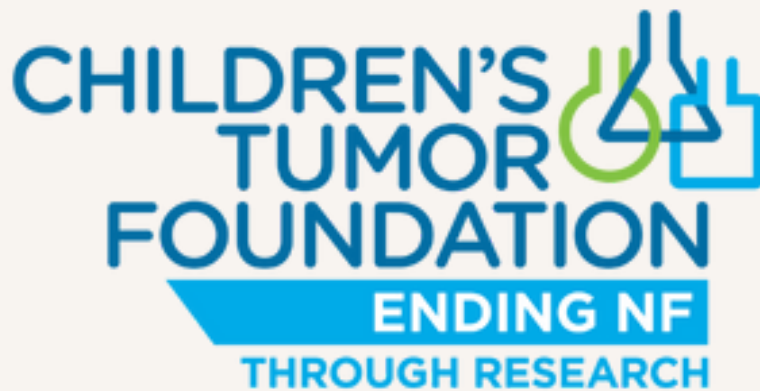
Dr. Eva Trevisson

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IPSEN

Innovation for patient care

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NFlection 
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AGENDA - DAY 1

08:00

Registration, Networking & Breakfast- Poster viewing opportunity

09:00

Introduction and Chairs Morning Session

Dr Grace Vassallo, Consultant Paediatric Neurologist and Clinical Lead HSS Complex
NF1 Service

Manchester University NHS Foundation Trust

Prof. Andy King, Professor of Neurosurgery, Manchester Centre for Clinical
Neurosciences, Salford Royal Hospital, Manchester Co-Director, Geoffrey Jefferson
Brain Research Centre, Manchester Academic Health Science Centre Northern Care
Alliance NHS Group, University

09:30

Keynote Lecture: 32 Years as an NF-ologist

Prof Gareth Evans, Professor in Medical Genetics and Cancer Epidemiology Clinical
Lead Manchester HSS NF2 Service, University of Manchester UK

09:50

History of NF in the UK

Dr. Sue Huson Clinical Geneticist & Meena Upadhyaya Distinguished Professor (Hon)
Division of Cancer and Genetics Cardiff University

10:00

A Phase I Study to Assess the Effect of Food on the Gastrointestinal (GI) Adverse
Events (AEs) and Pharmacokinetics (PK) of Selumetinib in Adolescents with
Neurofibromatosis Type 1 (NF1) Related Plexiform Neurofibromas (PN)

Prof David Viskochil-Department of Paediatrics, University of Utah, Salt, Lake City,
Utah, USA

10:10

Clinical characteristics and management of patients with neurofibromatosis 1 and
plexiform neurofibromas in Denmark: A nationwide study

Dr. Cecilie Ejerskov, Centre for Rare Diseases, Aarhus University Hospital, Denmark

10:20

Risk Factors in Pediatric Malignant Peripheral Nerve Sheath Tumours (MPNST): Results
from the French Pediatric Oncology Society (SFCE) cohort.

Dr Jordane Chaix – Paediatric and Adolescent Oncology, Gustave Roussy Cancer
Campus, Paris , France

AGENDA - DAY 1

10:30

Questions from Oral Presentations

10:40

Platform trials as an opportunity to identify new treatments in NF: identifying potential participating centres

Panel: Rianne Oostenbrink (chair) 1, Britt Dhaenens¹, Jonas Leubner², Eric Legius³

¹ ErasmusMC- Sophia's Children's Hospital, Rotterdam, The Netherlands.

² Charité-Universitätsmedizin Berlin, Berlin, Germany

³ Katholic University Leuven, Belgium

11:30

Challenges in NF2 novel therapy research, a patient non-profit perspective. 4 years of updates, challenges and innovation by NF2 BioSolutions. Gilles Atlan - Vice President NF2 BioSolutions

Sporadic and NF2 Schwannomatosis Vestibular Schwannomas Share Homogeneous Tumour Microenvironments- Grace Gregory, PhD Student (NF2 Biosolutions), University of Manchester

High dimensional imaging highlights the T-cell compartment as a viable therapeutic target in the vestibular schwannoma tumour microenvironment- Adam Paul Jones, PhD Student (NF2 Biosolutions), University of Manchester

12:15

POPLAR-NF2: A Parallel-group, Two-staged, Phase 2/3, Randomized, Multicenter Study to Evaluate the Efficacy and Safety of REC-2282 in Participants with Progressive NF2 Mutated Meningiomas

Glenn Morrison, Recurison Pharmaceutical Inc

12:30

Lunch and Networking Break.

Poster Viewing and Special Interest Breakout Sessions

Breakout session 1 (LEVEL 4 PARK LANE): NF1 Neuromuscular Special Interest Group- Lead Dr. Amish Chinnoy Is NF1 muscle weakness due to neurological ('central') or muscular ('peripheral') pathology? With Contributions from Dr. Siobhan West Consultant Paediatric Neurologist for the complex NF1 service and Prof. Ir. Hans Degens, Professor of Muscle Physiology, Visiting Professor, Lithuanian Sports University, Kaunas Department of Life Sciences Research Centre for Musculoskeletal Science & Sports Medicine Manchester Metropolitan University

Breakout session 2 (LEVEL 4 PARK AVENUE): NF2/ Schwannomatosis Special Interest Group- Lead Prof Gareth Evans What do we still need for NF2/Schwannomatosis? Invited Speaker-Cristina Perez-Becerril- Research Associate, University of Manchester - Improving sensitivity for detection of pathogenic variants in familial NF2-related schwannomatosis

AGENDA - DAY 1

13:30

Chair afternoon: Prof G. Evans
Professor in Medical Genetics and Cancer Epidemiology Clinical Lead Manchester HSS
NF2 Service
University of Manchester UK

13:30

Keynote Lecture: SPRED 1
Prof Eric Legius, Professor of Human Genetics, University of Leuven Belgium

14:00

Molecular Diagnosis of Mosaic Disease in the NF1 clinic
Dr. Emma Burkitt-Wright Consultant Clinical Geneticist HSS Complex NF1 service
Manchester, Manchester University Hospital NHS Foundation Trust

14:10

Creation of the international NF Variant Curation Expert Panel to improve genetic testing of NF-SCHW genes
Elisabeth Castellanos, Clinical Genomics Research Group, Germans Trias & Pujol Research Institute (IGTP); Genetics Service, Clinical Laboratory North Metropolitan (LCMN), Germans Trias & Pujol University Hospital (HUGTiP), Can Ruti Campus, Badalona, Barcelona, Spain

14:20

Questions from Presentations

14:25

Phase 2a randomized, double blind, vehicle-controlled trial of NFX-179 Gel in Persons with Neurofibromatosis Type 1 with cutaneous neurofibromas.
Gerd Kochendoerfer, PhD NFlection Therapeutics

14:40

How we image NF1
Dr. Calvin Soh Consultant Neuroradiologist HSS Complex NF1 Service Manchester
University Hospital NHS Foundation Trust

14:50

Diagnostic and classification challenges of NF1-related gliomas
Ms Tina Karabatsou Consultant Neurosurgeon HSS Complex NF1 Service Manchester
University Hospital NHS Foundation Trust and Northern Care Alliance NHS Foundation
Trust and Professor Federico Roncaroli Professor of Neuropathology Northern Care
Alliance NHS Foundation Trust and The University of Manchester

AGENDA - DAY 1

15:10

Questions from Case Presentations

15:20

Networking, Coffee Break and Poster Viewing Opportunity

15:40

Chairs- Dr Shruti Garg and Dr Emma Burkitt- Wright

Dr Shruti Garg – Consultant in Child and Adolescent Psychiatry, Manchester University NHS Foundation Trust and Clinical Research Fellow The Institute of Brain, Behaviour and Mental Health, University of Manchester

Dr Emma Burkitt-Wright, Consultant Clinical Geneticist HSS Complex NF1 service Manchester, Manchester University Hospital NHS Foundation Trust

15:40

Keynote Presentation: Epidemiology of NF1 and NF2 in Finland
Prof Juha Petonen, Cancer Research Unit and institute of Biomedicine
University of Turka Finland

16:10

Prevention of neurological signs and symptoms in children with NF1 and Brain stem gliomas-When is too little too late?

Dr. Grace Vassallo, Consultant Paediatric Neurologist and Clinical Lead HSS Complex NF1 Service Manchester University Hospital NHS Foundation Trust

Dr Emily Wilkins, Paediatric Trainee North West Deanery

16:20

Generic Health-Related Quality of Life: Analysis of the Pediatric Quality of Life Inventory and Child Health Questionnaire in children with Neurofibromatosis Type 1

Dr Britt Dhaenens, Department of General Paediatrics, ErasmusMC-Sophia's Children's Hospital, Rotterdam, The Netherlands

16:30

The course of intellectual development in children with Neurofibromatosis Type 1 based on longitudinal history study

A.M. (Sandra) van Abeelen, Kempenhaeghe, Center for Neurological Learning Disabilities, Netherlands

AGENDA - DAY 1

16:40

Questions from Oral Presentations

16:50

Opportunities from CTF Europe
Marco Nievo PhD, Chief Scientific Officer CTF Europe.

17:00

Chairs: Dr. Grace Vassallo and Prof Ian Kamaly-Asl
Dr Grace Vassallo Consultant Paediatric Neurologist and Clinical Lead HSS Complex NF1 Service
Professor Ian Kamaly-Asl, Professor of Paediatric Neurosurgery, Manchester University NHS Foundation Trust and University of Manchester

17:00

Keynote Lecture: Key neuroradiological features in Paediatric NF1 and NF2
Prof Stavros Stivaros, Professor Paediatric Neuroradiology and Translational Imaging, University of Manchester UK

17:30

Close of Event Day 1

19:00

Conference Meal, Awards and Entertainment

AGENDA - DAY 2

08.00- 09:00

Registration & Breakfast - Networking & Poster viewing

08:00

Symposium: Call for an international consortium for the validation of the cNFSkinindex questionnaire and other patient reported outcome measures in NF

Laura Fertitta¹ and Britt Dhaenens², Rianne Oostenbrink², Pierre Wolkenstein¹
¹ Department of Dermatology, National Referral Center for Neurofibromatoses, Henri Mondor Hospital, Assistance Publique - Hôpitaux de Paris (AP-HP), Créteil, France.
² Department of General Paediatrics, Erasmus MC- Sophia's Children's Hospital, Rotterdam, The Netherlands.

09:00

Chairs: Dr Alexander Lee and Prof Ian Kamaly Asl

Dr Alexander Lee, Consultant Medical Oncologist, The Christie NHS Foundation Trust and HSS Complex NF1 Service Manchester University Hospital NHS Foundation Trust
Professor Ian Kamaly-Asl, Professor of Paediatric Neurosurgery, Manchester University NHS Foundation Trust and University of Manchester

09:00

Keynote Lecture: MPNST

Prof Rosalie Ferner, Professor of Neurology/National Lead
Guy's and St Thomas' Foundation Trust and HSS Complex NF1 Service in the UK

09:30

Therapeutics discovery using synthetic lethal pharmacogenomic screens reveals vulnerability in MPNSTs harboring loss of function mutations in the gene encoding products of the polycomb repressive complex 2 (PRC2)

Prof Christopher L. Moertel, University of Minnesota School of Medicine, University of Minnesota Masonic Children's Hospital

09:40

Overall survival amongst patients with neurofibromatosis type 1 and malignant peripheral nerve sheath tumor

Stine Bogetofte Thomasen, Research Student, Aarhus University Hospital, Denmark

09:50

Increased risk of endocrine morbidity in individuals with NF1: A Danish population-based cohort study

Line Kenborg, Senior Scientist, Danish Cancer Society Research Center

10:00

Questions from Oral Presentations

AGENDA - DAY 2

10:10

Keynote Lecture: Treatment of Ependymoma in NF2
Prof Michel Kalamarides, Professor and Director of Neurosurgery
Pitie-Salpetriere Hospital

10:40

Radiation treatment of benign tumours in NF2-schwannomatosis: a national study of 266 irradiated patients showing a significant increase in malignancy
Prof Gareth Evans, Professor in Medical Genetics and Cancer Epidemiology Clinical Lead
Manchester HSS NF2 Service University of Manchester UK

10:50

Challenges of a giant thoracic meningocele with insights from the histology
Mr Joshi George, Consultant Neurosurgeon HSS Complex NF1 Service Manchester
University Hospital NHS Foundation Trust and Northern Care Alliance NHS Foundation
Trust

11:00

Keynote Lecture: Animal Models in NF
Prof Marco Giovannini, Professor of Neck and Head Surgery, University of California Los
Angeles

11:30

Poster Presentations - Mezzanine floor - 11:30am - 13:00pm

11:30

Breakout sessions - 11:30am - 13:00pm

Breakout Session 1 (LEVEL 4 PARK LANE): Mental Health In NF Special Interest Group-
Leads Dr Shruti Garg , Louise Robinson and Andre Reitman

Breakout session 2 (LEVEL 4 PARK AVENUE): Update on the International
Neurofibromatosis and Schwannomatosis Genes Variant Curation Expert Panel (VCEP)”
Prof Scott Plotkin and Dr. Elisabeth Castellanos Germans Trias & Pujol Research
Institute (IGTP) and Coordinator of Clinical Genomics Unit at Clinical Laboratory of
North Metropolitan (LCMN) located at Hospital University Germans Trias &
Pujol. Badalona, Barcelona (Catalonia, Spain).

12:00

Lunch and Networking

AGENDA - DAY 2

13:00

Parallel sessions: Oral Presentations NF1/NF2

NF1 - International Suite - Level 3

Chairs:

Professor Ros Ferner Professor of Neurology and National Lead Guy's and St Thomas' Foundation Trust and HSS Complex NF1 Service in the UK

Dr John Ealing Consultant Neurologist HSS Complex NF1 Service Manchester University NHS Foundation Trust and Northern Care Alliance NHS Trust

NF2- Senate Suite - Level 2

Chairs:

Professor Andy King, Professor of Neurosurgery, Manchester Centre for Clinical Neurosciences, Salford Royal Hospital, Manchester, Co-Director, Geoffrey Jefferson Brain Research Centre, Manchester Academic Health Science Centre, Northern Care Alliance NHS Group, University of Manchester, Manchester, UK,

Dr Claire Forde, Consultant Clinical Geneticist HSS NF2 service Manchester, Manchester University Hospital NHS Foundation Trust

<p>NF1 - International Suite - Level 3 Chairs: Professor Ros Ferner Professor of Neurology and National Lead Guy's and St Thomas' Foundation Trust and HSS Complex NF1 Service in the UK Dr John Ealing Consultant Neurologist HSS Complex NF1 Service Manchester University NHS Foundation Trust and Northern Care Alliance NHS Trust</p>	<p>NF2 - Senate Suite - Level 2 Chairs: Professor Andy King, Professor of Neurosurgery, Manchester Centre for Clinical Neurosciences, Salford Royal Hospital, Manchester, Co-Director, Geoffrey Jefferson Brain Research Centre, Manchester Academic Health Science Centre, Northern Care Alliance NHS Group, University of Manchester, Manchester, UK, Dr Claire Forde, Consultant Clinical Geneticist HSS NF2 service Manchester, Manchester University Hospital NHS Foundation Trust</p>
<p>Comparison of a STIR- and T1-weighted-based radiomics model to differentiate between plexiform neurofibromas and malignant peripheral nerve sheath tumors in neurofibromatosis type 1 Professor Scott Plotkin, Professor of Neurology, Harvard</p>	<p>Multiple meningiomas as a criterion for the diagnosis of Neurofibromatosis Type 2 and other tumor predisposition syndromes Dr. Cathal Hannan, Neurosurgery, Manchester Centre for Clinical Neurosciences</p>
<p>Pregnancy and the risk for cancer among women with neurofibromatosis type 1 Roope Kallionpää, Senior Researcher Institute of Biomedicine, University of Turku, Finland</p>	<p>Antisense oligonucleotides targeting exon 11 are able to partially rescue the Neurofibromatosis Type 2 phenotype in vitro. Núria Catasús, Postdoctoral researcher, Germans Trias i Pujol Research Institute (IGTP)</p>
<p>Synthetic lethal screening identifies existing autophagy drugs with selective viability effects on Neurofibromatosis type-1 model systems Megan Stevens, Post-doctoral researcher, The Living Systems Institute, University of Exeter, Exeter, UK</p>	<p>Reprogram the tumor microenvironment to prevent tumor-induced hearing loss and augments treatment efficacy in NF2 schwannoma rodent models Dr. Lei Xu, Assistant Professor, Massachusetts General Hospital</p>
<p>Unbalancing the Ras/MAPK pathway and the cAMP/PKA pathway as a therapeutic strategy for cutaneous neurofibromas Dr. Eduard Serra, Group Leader, Germans Trias i Pujol Research Institute (IGTP)</p>	<p>Susceptibility locus for sporadic vestibular schwannoma identified by genome-wide association analysis Dr Miriam Smith, Senior Lecturer in Cancer Genomics, The University of Manchester</p>
<p>Aberrant GABAergic neuronal development leads to disrupted contactin expression in a human induced pluripotent stem cell model of Neurofibromatosis 1-Autism Julietta O'Flaherty, PhD student, Division of Cell Matrix Biology & Regenerative Medicine, University of Manchester</p>	<p>The inflammatory and microvascular microenvironment in sporadic and neurofibromatosis type II related vestibular schwannoma (VS): a comparative imaging and pathology study Daniel Lewis, University of Manchester</p>
<p>A case-only study in 1,333 neurofibromatosis type 1 patients to identify common genetic modifiers of cutaneous, subcutaneous, and plexiform neurofibromas Laurence Pacot, PhD student, PharmDAP-HP, Centre - Université Paris Cité</p>	<p>"Immunogenic subtype" characterised by macrophages infiltration predominantly comprise meningiomas in neurofibromatosis type 2 patients Dr. Yu Teranishi, Assistant Professor, The University of Tokyo Hospital, Department of Neurosurgery</p>

AGENDA - DAY 2

14:00

Questions from Parallel Sessions
NF1 - Park Lane Suite - Level 4 NF2 - Park Avenue Suite - Level 4
Questions

14:15

Networking and Coffee Break

14:35

Chairs - Dr Grace Vassallo and Professor John-Paul Kilday
Dr. Grace Vassallo- Consultant Paediatric Neurologist and Clinical Lead HSS
Complex NF1 Service Manchester University Hospital NHS Foundation Trust.
Prof JP Kilday Consultant Paediatric Neurooncologist for the Complex NF1 service.

14:35

The ultimate in MDT work-Paediatric NF1 case.
Dr. Grace Vassallo- Consultant Paediatric Neurologist and Clinical Lead HSS
Complex NF1 Service Manchester University Hospital NHS Foundation Trust.
Dr. Amish Chinoy Consultant Paediatric Endocrinologist and Prof Z Mughal
Consultant Metabolic Bone Medicine Complex NF1 Manchester
Mr. A. Tambe Consultant Paediatric Spinal Surgeon for the Complex NF1 service
Manchester
Prof JP Kilday Consultant Paediatric Neurooncologist for the Complex NF1 service.
Dr Vivien Tang Consultant Paediatric Radiologist HSS C HSS Complex NF1 Service
Manchester University Hospital NHS Foundation Trust

14:45

Can Selumetinib delay the need for surgery in Neurofibromatosis Type 1 (NF1) with
a Spinal Phenotype? - a multi-disciplinary approach
Dr Alexander Lee, Consultant Medical Oncologist, The Christie NHS Foundation
Trust and HSS Complex NF1 Service Manchester University Hospital NHS
Foundation Trust

14:55

Questions from Case Study

15:00

Keynote Presentation: Medical Therapy in NF2
Prof Scott Plotkin, Professor of Neurobiology, Harvard

AGENDA - DAY 2

15:30

Symposium: Advancing treatments for NF1 related cognitive and behavioural difficulties

Dr. Shruti Garg, Consultant in Child and Adolescent Psychiatry and Clinical Research Fellow

The Institute of Brain, Behaviour and Mental Health, University of Manchester, UK

15:30

Overview and Introduction

15:40

Insights from longitudinal studies of brain development in NF1 (EDEN study).
Professor Emily Jones , Professor of Translational Neurodevelopment, Birkbeck College , London

16:00

Cortical oscillatory activity in NF1
Samantha Booth, PhD Student University of Manchester

16:20

Early intervention studies in infancy
Prof Jonathan Green, Professor of Child/Adolescent Psychiatry University of Manchester and Honorary Consultant Child & Adolescent Psychiatrist at Manchester University NHS Trust

16:40

Novel interventions in NF1
Dr Shruti Garg, Garg Consultant in Child and Adolescent Psychiatry, Royal Manchester Children's Hospital and Clinical Senior Lecturer at University of Manchester

17:00

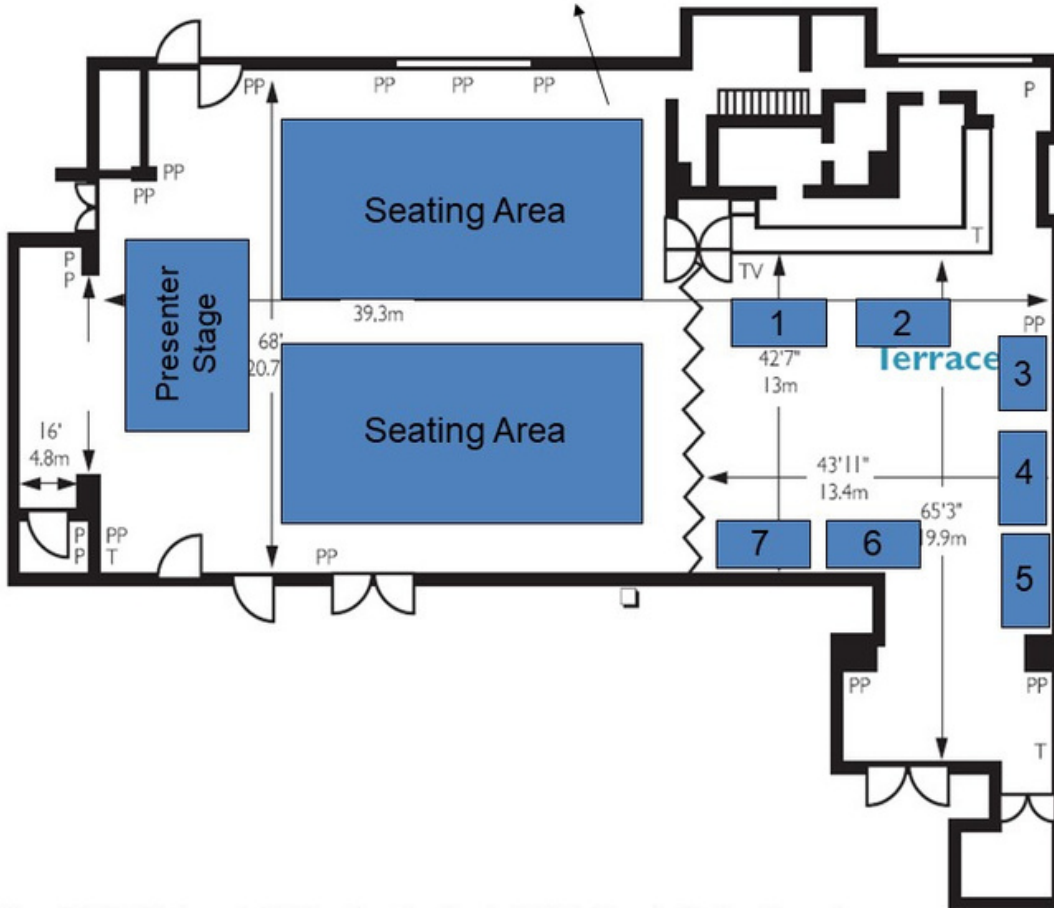
Close of Event Prof Evans and Dr. G.Vassallo

17:30

Close of Event

FLOORPLAN

International Suite



Level 3 - International Suite

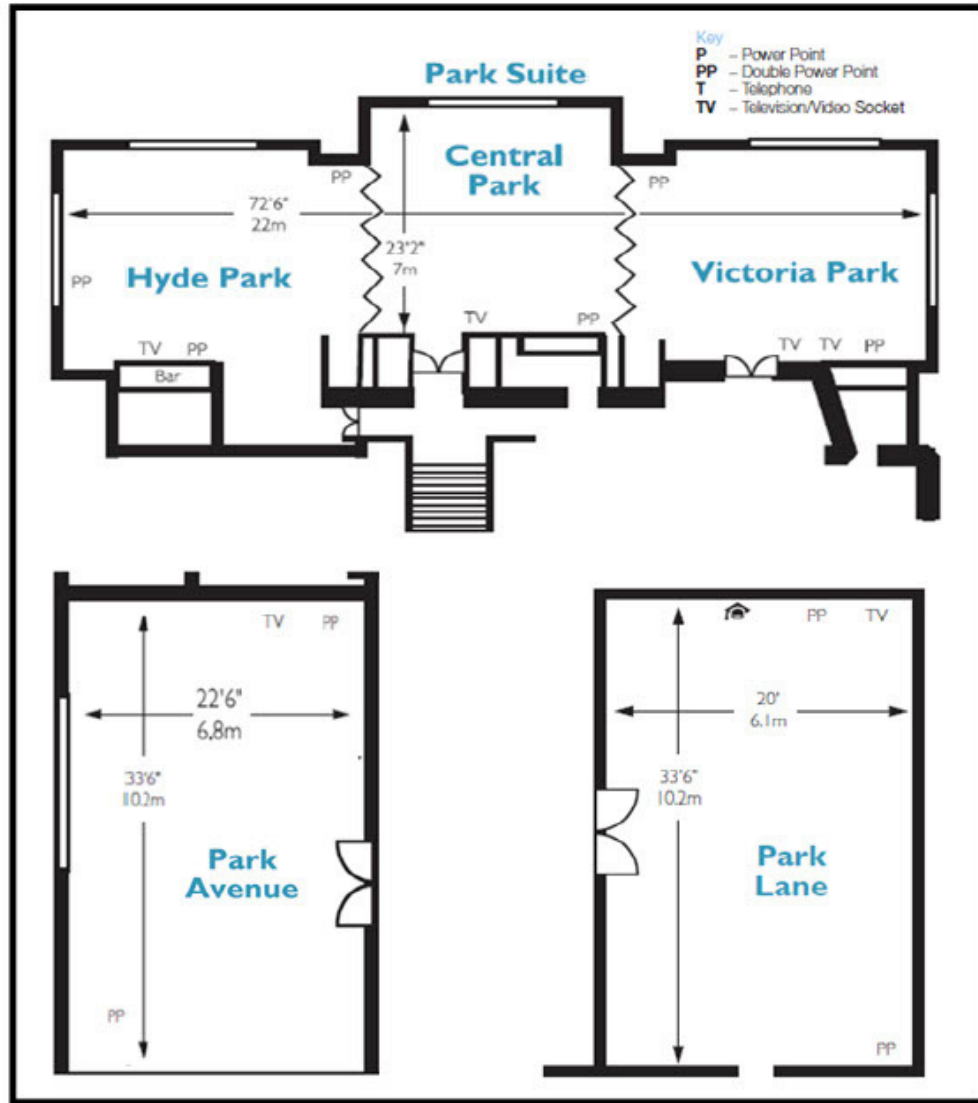
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FLOORPLAN



Level 4 - Park Avenue and Park Lane

Level 4 - Toilets

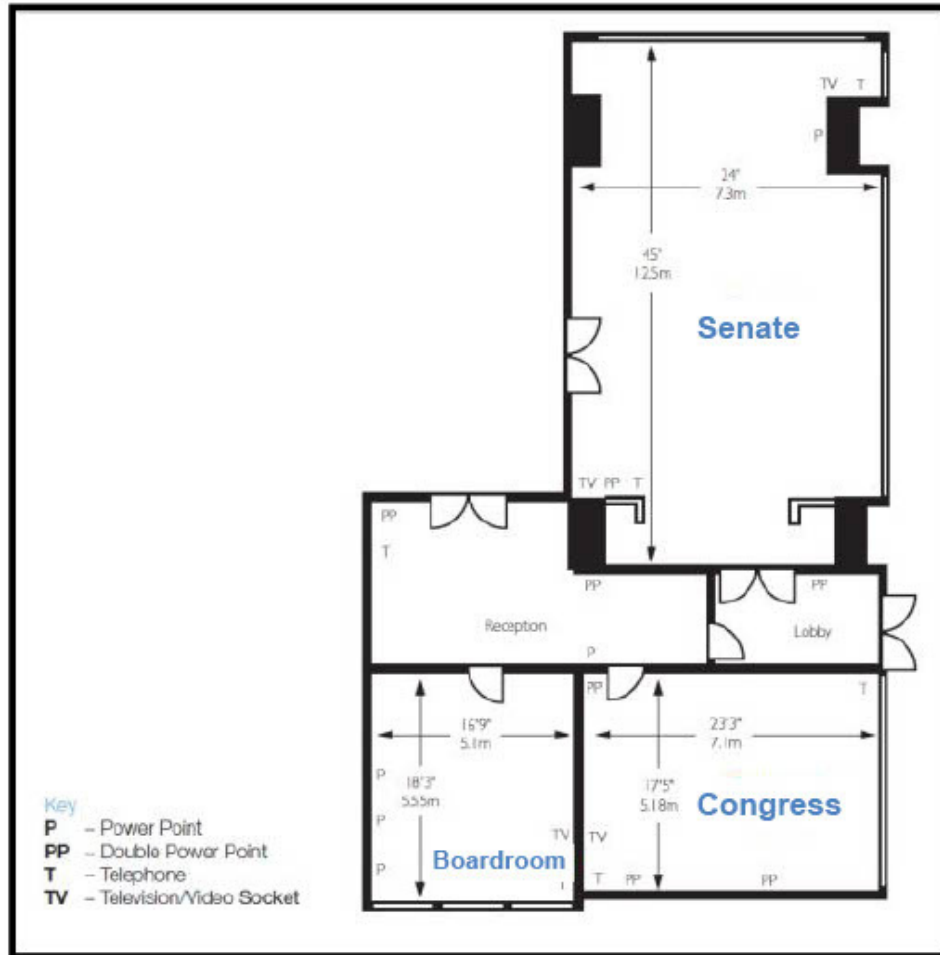
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FLOORPLAN



Level 2 - Senate

Level 2 - Toilets

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CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

SAVE THE DATE

2023
NF CONFERENCE
JUNE 24 - 27, 2023

FAIRMONT PRINCESS HOTEL
SCOTTSDALE, ARIZONA



Manchester NF EURO 2022

We hope you enjoy the conference

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