



## Office for Rare Conditions: Past Events/Engagements

Date	Event	Clinical team/Patient association	Main organiser	Location
<b>Saturday 23/11/2019</b>	Festive Fun Event	Office for Rare Conditions	Office for Rare Conditions	Touchbase business centre, Kinning park, Glasgow
<b>Friday 08/11/2019</b>	Glasgow Paediatric Research Day	University of Glasgow, Child Health	Office for Rare Conditions	Teaching and learning centre, QEUH and RHC hospital Campus
<b>Saturday 05/10/2019</b>	Scottish Meeting Primary Ciliary Dyskinesia	Primary Ciliary Dyskinesia Family Support Group Office for Rare Conditions	Primary Ciliary Dyskinesia Family Support Group Office for Rare Conditions	Lab Building, QEUH, Glasgow
<b>Saturday 07/09/2019</b>	Klinefelter's Syndrome Association Information Event	Klinefelter's Syndrome Association Office for Rare Conditions	Klinefelter's Syndrome Association Office for Rare Conditions	Lab Building, QEUH, Glasgow
<b>Monday 02/09/2019</b>	Early Management of Rare Conditions in the Neonate	Dr Martina Rodie Office For Rare Conditions	Office for Rare Conditions	New Lister Building, Glasgow Royal Infirmary
<b>Saturday 31<sup>st</sup> August 2019</b>	Scottish Meeting Tuberous Sclerosis Association	Tuberous Sclerosis Association Office for Rare Conditions	Tuberous Sclerosis Association Office for Rare Conditions	Lab Building, QEUH, Glasgow
<b>Saturday 15/06/2019</b>	Family Fund Information Event		Family Fund Office for Rare Conditions	Lab Building, QEUH, Glasgow
<b>Saturday 08/06/2019</b>	Scottish Differences of Sex Development Network Family Day 2019	Dr Martina Rodie, Consultant Neonatologist	Scottish Differences in Sex Development Network	The Studio, Hope St Glasgow.
<b>Saturday 23/03/2019</b>	Rare Resource Toolkit Launch for patients and families	Genetic Alliance UK	Genetic Alliance UK Office for Rare Conditions	Touchbase Centre Kinning Park Glasgow
<b>Monday 18/03/2019</b>	Rare Resource Toolkit Launch for professionals	Genetic Alliance UK	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow

<b>Saturday 02/03/2019</b>	Rare Disease Day- Fun Event for Children	Office for Rare Conditions	Office for Rare Conditions	Touchbase Centre Kinning Park Glasgow
<b>Tuesday 04/12/2018</b>	Web Rounds for Rare Bone Conditions- Hypophosphatasia, Diagnosis & Management	Professor Faisal Ahmed Complex Bone Service	Office for Rare Conditions	Child Health Web Round Endo ERN platform
<b>Saturday 10/11/2018</b>	Stickler Syndrome Information Day	Dr Margo Whiteford Clinical Genetics	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Thursday 08/11/2018</b>	PULSE live GP Conference-Stand & 4 lightning talks	Dr Martina Rodie Liz Dougan	PULSE magazine	Scottish Conference Centre
<b>Saturday 03/11/2018</b>	Achondroplasia Family Day	Dr Avril Mason Complex Bone Service	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Wednesday 10/10/2018</b>	Glasgow Rare Disease Showcase Stand & Presentation	Dr Martina Rodie Liz Dougan	Findacure	University of Strathclyde Glasgow
<b>Tuesday 02/10/2018</b>	Information event-Undiagnosed & Rare Conditions.	SWAN UK Clinical Genetics	SWAN UK Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Saturday 22/09/2018</b>	Primary Ciliary Dyskinesia - Stand	PCD support.org.uk	PCD UK	The Lighthouse, Glasgow
<b>Saturday 08/09/2019</b>	Klinefelter Syndrome/XXY meeting	KSA.org	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Monday 03/09/2018</b>	Early Management of Rare Conditions in the Neonate	Dr Martina Rodie Consultant Neonatologist	Dr Martina Rodie Office for Rare Conditions	Teaching & Learning Centre QEUH, Glasgow
<b>Saturday 25/08/2018</b>	Tuberous Sclerosis Scottish AGM	TSA Office for Rare Conditions	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Saturday 11/08/2018</b>	Rare Conditions Family Fun Event	Office for Rare Conditions	Office for Rare Conditions	Touchbase Centre Kinning Park, Glasgow
<b>Saturday 16/06/2018</b>	Hypospadias Family Information Day	Professor Faisal Ahmed DSD Team	Professor Ahmed Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Saturday 09/06/2018</b>	Turner's Syndrome Society Family Information Event	Turner's Syndrome Society	Turners Syndrome Society Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Friday 04/05/2018</b>	Clinical Trials and Genetic Disease	Clinical Genetics	Clinical Genetics	Teaching & Learning Centre

			Office for Rare Conditions	QEUH, Glasgow
<b>Saturday 03/03/2018</b>	Family Information Event	Office for Rare Conditions	Office for Rare Conditions	Lab Building Seminar Room 1 QEUH & RHC Glasgow
<b>Friday 02/03/2018</b>	Rare Disease Event -Education Forum Grand Round, QEUH	Office for Rare Conditions	Office for Rare Conditions	Teaching & Learning Centre QEUH, Glasgow
<b>Wednesday 28/02/2018</b>	Fun Event for Children – Rare Disease Day	Office for Rare Conditions	Office for Rare Conditions	Partick borough Hall Glasgow
<b>Tuesday 27/02/2018</b>	Rare Disease Day Educational Forum	Office for Rare Conditions	Office for Rare Conditions	QEUH & RHC Campus
<b>Saturday 04/11/2017</b>	Von Hippel Lindau Syndrome Scottish Patient AGM	VHL UK	VHL UK Office for Rare Conditions	Lab Building Seminar Room 1 QEUH Glasgow
<b>Thursday 19/10/2017</b>	RDUK Project	RDUK	RDUK Office for Rare Conditions	Main Atrium RHC Glasgow
<b>Saturday 30/09/2017</b>	Di George syndrome Family Meeting	Clinical Genetics	Grace Macleod Specialist Genetics Nurse Office for Rare Conditions	Lab Building Seminar Room 1 QEUH Glasgow
<b>Wednesday 20/09/2017</b>	Providing Best Care for patients with Tuberous Sclerosis	Professor Alan Jardine Renal Medicine	Professor Jardine Office for Rare Conditions	Lab Building Seminar Room 3
<b>Monday 04/09/2017</b>	Early Management of Rare Conditions in the Neonate	Dr Martina Rodie, Neonatology	Dr Martina Rodie Office for Rare Conditions	Teaching & Learning Centre QEUH Glasgow
<b>Thursday 06/07/2017</b>	MDT roles in Prader-Willi service	Dr Guftar Shaikh Paediatric Endocrinologist	Endocrinology MDT Office for Rare Conditions	Teaching & Learning Centre QEUH Glasgow
<b>Thursday 15/06/2017</b>	Duchenne Muscular Dystrophy Bone Symposium	Developmental Endocrinology Research Group, University of Glasgow  Action Duchenne Muscular Dystrophy UK	Dr Jarod Wong Office for Rare Conditions	Teaching & Learning Centre QEUH, Glasgow