

PROGRAMME

10 am

9.30 am registration 12.15 pm talk: pain management & mindfulness

WITH NEUROFBROMATOSIS TYPE 1

Mary Thomas, Clinical Nurse Specialist,

WELCOME COMMENTS GSTT London

Karen Cockburn, Charity Director,
Nerve Tumours UK

1 pm
LUNCH

10.15 am talk: the ntuk helpline 1.45 pm talk: how to claim benefits/ pip

Rebecca Rennison, Specialist NF Nurse FOR NEUROFIBROMATOSIS TYPE 1

Speaker - TBC

11 am TALK: HOW TO MANAGE YOUR NF1 2.30 pm QUESTIONS & ANSWERS PANEL

Dr. Joshua Hersheson, Consultant All Speakers, Open Session Neurologist, GSTT London

12 pm Break 3 pm Closing remarks

Karen Cockburn

Nerve Tumours UK

First Floor, 44 Coombe Lane, London SW20 0LA nervetumours.org.uk • info@nervetumours.org.uk • 020 8439 1234





BROMLEY NF1 INFORMATION DAY FEEDBACK FORM

Please rate the events by circling your answers to each question:

DID THE EVENT MEET YOUR EXPECTATIONS?

| 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
|-----------|--|---|---|---|---|--|---|--|--|
| id not | | | | | | | Exceeded them | | |
| | | | | RECOMN | MEND TH | IE EVEN | T TO FAN | IILIES | |
| 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| nlikely | | | | | | | Ve | ry likely | |
| ALL HOV | w wou | LD YOU F | RATE THE | EVENT | ? | | | | |
| 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| nhelpful | | | | | | | Very | helpful | |
| ORGANI | SED WA | AS THE E | VENT? | | | | | | |
| 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| norganise | ed | | | | | | Very or | ganised | |
| THE EVE | NT TOC | LONG, 1 | 00 SHO | RT OR AE | BOUT RIC | GHT? | | | |
| 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | |
| ort | | | | | | | | Too long | |
| let us kn | ow any o | other thou | ights or co | omments y | ou may l | nave: | | | |
| | | | | | | | | | |
| | | | | | | | | ······································ | |
| | | | | | | | | | |
| | ••••• | | | | | •••••• | | ······································ | |
| | id not LIKELY NDIVID 2 nlikely ALL HOV 2 nhelpful ORGANI 2 norganise THE EVE 2 | id not LIKELY IS IT THE NDIVIDUALS WE 2 3 and ikely ALL HOW WOULD 2 3 and elpful ORGANISED WA 2 3 anorganised THE EVENT TOO 2 3 anorganised | LIKELY IS IT THAT YOU NDIVIDUALS WITH NF? 2 3 4 milikely ALL HOW WOULD YOU F 2 3 4 mhelpful ORGANISED WAS THE E 2 3 4 morganised THE EVENT TOO LONG, 1 | LIKELY IS IT THAT YOU WOULD INDIVIDUALS WITH NF? 2 | LIKELY IS IT THAT YOU WOULD RECOMM NDIVIDUALS WITH NF? 2 3 4 5 6 Inlikely ALL HOW WOULD YOU RATE THE EVENT 2 3 4 5 6 Inhelpful ORGANISED WAS THE EVENT? 2 3 4 5 6 Inorganised THE EVENT TOO LONG, TOO SHORT OR AE 2 3 4 5 6 | LIKELY IS IT THAT YOU WOULD RECOMMEND THE NDIVIDUALS WITH NF? 2 3 4 5 6 7 Inlikely ALL HOW WOULD YOU RATE THE EVENT? 2 3 4 5 6 7 Inhelpful ORGANISED WAS THE EVENT? 2 3 4 5 6 7 Inorganised THE EVENT TOO LONG, TOO SHORT OR ABOUT RICE 2 3 4 5 6 7 Ort | LIKELY IS IT THAT YOU WOULD RECOMMEND THE EVENT NDIVIDUALS WITH NF? 2 3 4 5 6 7 8 Inlikely ALL HOW WOULD YOU RATE THE EVENT? 2 3 4 5 6 7 8 Inhelpful ORGANISED WAS THE EVENT? 2 3 4 5 6 7 8 Inorganised THE EVENT TOO LONG, TOO SHORT OR ABOUT RIGHT? 2 3 4 5 6 7 8 | LIKELY IS IT THAT YOU WOULD RECOMMEND THE EVENT TO FAMINDIVIDUALS WITH NF? 2 3 4 5 6 7 8 9 Inlikely Very Organised Very or THE EVENT TOO LONG, TOO SHORT OR ABOUT RIGHT? 2 3 4 5 6 7 8 9 Interpretation of the Event Too Long, Too Short or About Right? | |