

## Fragile X Society policy for family media volunteers 2020

### Background

The aim of The Fragile X Society is to support and empower individuals and families affected by Fragile X<sup>1</sup>. An important step to improving experiences for people with Fragile X is to raise awareness among the general public of these conditions, as well as tackling stigma relating to disability, and how they influence the lives of those affected. Our ultimate aim is that through raising awareness we can facilitate an improvement in the lives of our members through the provision of appropriate public services and health care services.

Thank you for volunteering to talk to the media about your experiences of Fragile X. Sharing your family's personal story will help us make people more aware of what Fragile X is, and the challenges and triumphs that a family experiences when they are living with a genetic condition.

This policy summarises how The Fragile X Society will work with you. It provides information on how we will contact you, how we will get your feedback and sign-off regarding the information we write about you, and how we will use your information. It also outlines our commitment to your privacy and the sensitive handling of your story. Once you have read this policy, please sign the section at the bottom to confirm you are happy with the process and commitments outlined and return this document to Pete Richardson

**Pete will be your main contact at The Fragile X Society. If you have any questions about this policy, Pete can be contacted at [pete@fragilex.org.uk](mailto:pete@fragilex.org.uk) or telephone 07400 611064**

Please note that media volunteers will not be general spokespeople for the Fragile X Society - If the media ask you about anything besides your own personal story, you will need to refer them to the Managing Director of the Fragile X Society.

### How will we support you?

Talking to the media (online, newspapers, magazines, radio, and local TV) may be a new experience for you.

We will provide you with the opportunity to take part in an interactive online media training session. This should help prepare you to become a media volunteer. You will be given an insight into how the media works, what sort of questions may be asked and how to write and feedback your stories, so that they will interest and positively influence readers and, in the case of radio, listeners!

Please look at the summary below which should help you understand what to expect when you volunteer to talk to the media on behalf of The Fragile X Society.

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<sup>1</sup> When we talk about Fragile X, we are referring to Fragile X Syndrome, as well as Fragile X premutation carriers and the conditions they may experience (Fragile X Primary Ovarian Insufficiency (FXPOI), Fragile X-Associated Tremor/Ataxia Syndrome (FXTAS) and other Fragile X Premutation Associated Conditions (FXPAC)).

Having received your initial interest to become a media volunteer, we ask you to sign and return this form. We want to be sure that you understand what being a media volunteer involves before you agree to go ahead.

- Once you have signed and returned this form, Pete will call you to introduce himself. In this telephone conversation, we will ask for some basic information from you about your experiences of Fragile X, and the topics which you would be happy to speak to the media about.
- We will ask for some photographs of your family, high quality if at all possible.
- We will write up the notes that we have made from your conversation and email them to you. This is so you can check the facts about your story and make any necessary changes.
- We will then keep your photos and information on file. Should we receive a media request which has a good fit with your family's story and discussion topics, we will send the notes and photos to the journalist.

- If a journalist expresses interest in your story, we will contact you to ask if you would be happy to talk to the journalist. If you are, then we will give the journalist your contact number and ask them to make arrangements to speak with you directly.
- In preparation for the interview, we will give you and the journalist a 'crib sheet' with a few points about Fragile X and the Fragile X Society. This will include language we prefer to be used when discussing Fragile X.

**Important things to note about journalistic process**

- A journalist cannot guarantee or insist to their editor that you receive final copy approval
- The night before a paper or magazine goes to print, a sub-editor will check the story and this person has the power to change headlines/captions at the last moment, so changes may be made that you have not approved.
- If an article appears online that you are unhappy with, we can ask the publication to change the copy / headline. It is possible, however, that they may not amend it. This is obviously not possible with printed articles
- We will do our best to place your story in the media. Unfortunately, we are not always successful, and you may find that your story is not used.
- It is important to be aware that, once your story is published, further publications may run your story with photographs without contacting you. This will only be based on the previous content you provided to your journalist contact.

*Please note that while we try to do all we can to ensure your story is portrayed in the way you would like it to be, The Fragile X Society does not have control over how a journalist, editor or broadcaster chooses to represent a story and therefore cannot be held responsible for the final content of an interview or article.*

**Important things to consider about your family's participation**

- It is important to consider the privacy and dignity of your child if you are disclosing information (such as medical details, challenges they face) on their behalf publicly, including how they may feel in the future about the information that has been disclosed about them.
- Discuss with all of your family members about the media volunteer opportunity and ensure that they are all comfortable with the volunteering, including the level of details you are willing to provide. We encourage you to consider the boundaries of what you would and would not like to discuss.
- If you wish to discuss the experience of an adult relative, this may only be done with their consent

**How will you know where your story has appeared in the media?**

Once your story has appeared, we will do our best to gather cuttings and/or recordings and send copies to you.

**What happens if you are contacted directly by a media organisation?**

Sometimes a story generates significant media interest and after the original publication other newspapers, magazines, and sometimes television companies, might contact you directly for an interview. If this happens to you, please do not engage in any discussion with the caller yourself but ask them to contact the Fragile X office. This is for two important reasons:

- 1) If we do not know who you have spoken to, we are unable to ensure that your story is presented in the way you want it to be. Within other Charities, families have spoken to the media without their knowledge and then been very distressed by the often sensationalist way in which their story has been portrayed.
- 2) We need to ensure that the media outlet that wishes to talk to you is fully informed about Fragile X and its associated conditions and will print an honest and accurate story.

### **How will we use your story in our publicity materials?**

Family stories and photographs are essential to create engaging materials such as fundraising guides, e-newsletters, posters, advertising, social media and our website. They help to motivate people to learn more about Fragile X, our charity, and how they can support.

If we would like to use your story and/or photographs in our publicity materials, we will:

- contact you to ask your permission
- draft the text that we would like to use and send it to you for approval
- send the final artwork of the materials before they are printed or made live.

By signing this policy, you give us permission to use your photos and story in perpetuity.

### **What is our commitment to you if you no longer wish your story/photographs to be used?**

If your family circumstances change or you change your mind about us using your story/photographs, please let us know as soon as possible, within five working days we will not use it in any future materials. If we have placed the story with a media outlet, we will contact them to withdraw it. We are sorry but will be unable to withdraw any printed materials that are already in use.

Your privacy is very important to us, here at the Fragile X Society. Please be assured that we will not:

- give out your contact number to a journalist unless we have your permission to do so
- give out your contact details to any third party.

All personal information held by The Fragile X Society is handled according to the Data Protection Act 1998 and in accordance with GDPR regulations. Permissions will be reviewed every 5 years and/or when a child turns 18 and becomes an adult.

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I confirm that I have read and understood the policy outlined above and agree with the process and terms.

SIGNED.....

PRINT NAME .....

ADDRESS.....

TELEPHONE NUMBERS .....

EMAIL .....

DATE .....

Please sign and return this document as soon as possible to [pete@fragilex.org.uk](mailto:pete@fragilex.org.uk)