

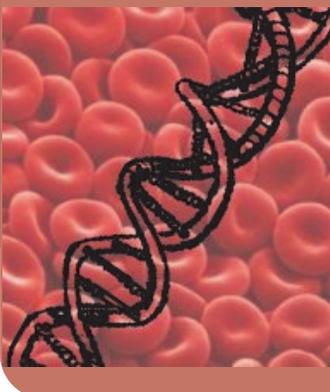
THANK YOU  
FOR YOUR  
PARTICIPATION  
IN OUR SURVEY!

Thank you to all IFAR participants who responded to the online feedback survey! Most of the 32 respondents identified as a parent or guardian of an individual with FA (84%). Some respondents were individuals with FA or FA-like symptoms (13%) and some were extended relatives of individuals with FA (3%). Most respondents (83%) were first enrolled in the IFAR sometime after 2005. 88% of respondents currently live in the United States, and 12% represent IFAR participants who live abroad. To those participants who wish to contribute more feedback, or to those who were not able to complete the survey, please contact us any time with your ideas! We always look forward to hearing from you.

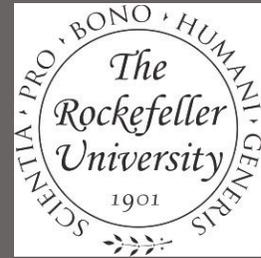
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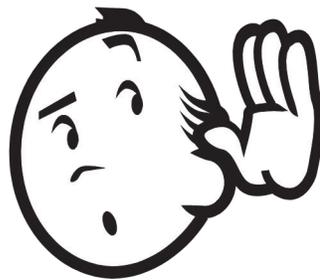


# The International Fanconi Anemia Registry



IFAR PARTICIPANT PERSPECTIVE SURVEY RESULTS

## Our First Step to Listening to your Feedback



The IFAR Participant Perspective Survey was an opportunity for us to learn about the opinions and needs of our participants. This feedback is important for us to maintain research goals that focus on the needs of individuals with FA and their families. We have analyzed the results of the survey and wish to share them with you. Most (82%) survey respondents indicated that it would be helpful to receive

the results of this study, and most (85%) respondents hope to receive more general updates from the IFAR in the form of newsletters. This newsletter was created with these preferences in mind. Thank you again for your participation and please continue to give us feedback and ideas of ways the IFAR can be more helpful to you and your family members.

## Focus of Future IFAR Research and Resources

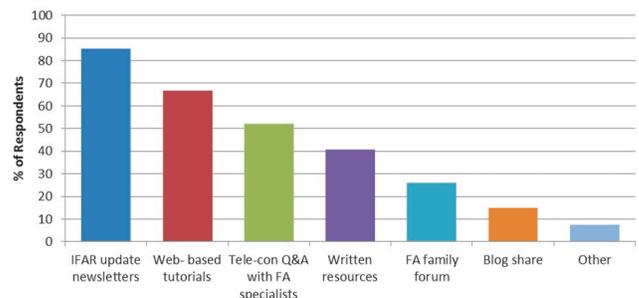
Most survey respondents (89%) stated that it is important IFAR research be centered around the needs of its participants and families. When survey respondents considered the focus of future IFAR research, one central theme emerged. The importance was placed on gathering information to support families as the life expectancy of FA increases: defining the relationship between an individual's genetic cause of FA and their symptoms over time, understanding FA cancer susceptibility, and describing issues that affect teens and adults with FA.

One participant described this priority by stating:

*"I am not familiar with all [the IFAR's] research projects currently underway, but I believe that since the BMTs are now far more successful than in the past, we need to move into improving the cancer prevention and/or treatment with FA patients."*

Respondents are interested in the IFAR developing educational resources like web-based tutorials and IFAR update newsletters. When asked which topics would be most helpful to feature through these resources, most respondents indicated an interest in receiving information for teenagers and adults with FA (78%), causes and control of DNA damage (70%), potential sources of financial assistance for families affected by FA (67%), and the steps to finding an individual's genetic cause of FA (59%).

Respondents' interest in potential IFAR resources

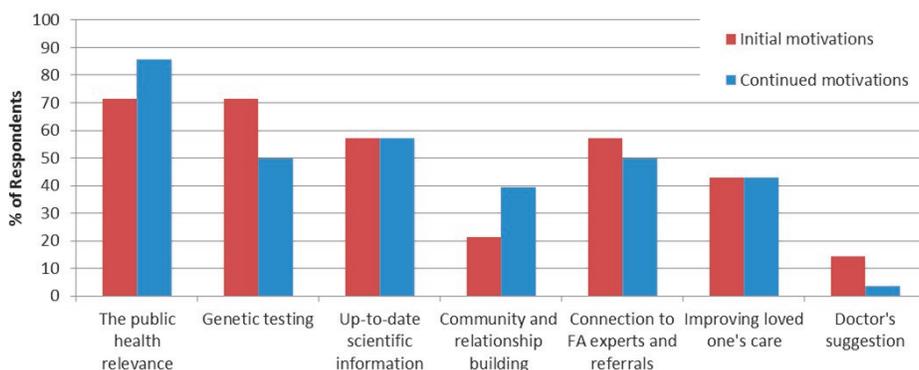


To get a better sense of what individuals with FA and their families like and dislike about participation in the IFAR, survey respondents were asked to tell us about their motivations in initially joining the study and continuing to participate in the study and what they feel are challenges to participation. We also wanted to know what current IFAR services are used most often and which services are the most helpful. This information can be used to make the IFAR more helpful to you and your family.

## Motivations for IFAR Participation

Survey respondents are most likely to initially and continually participate in the IFAR for the public health relevance and personal benefit of genetic testing over all other motivations. They are also more likely to continue to participate in the IFAR for the public health relevance than for the personal benefit of genetic testing offered through the study.

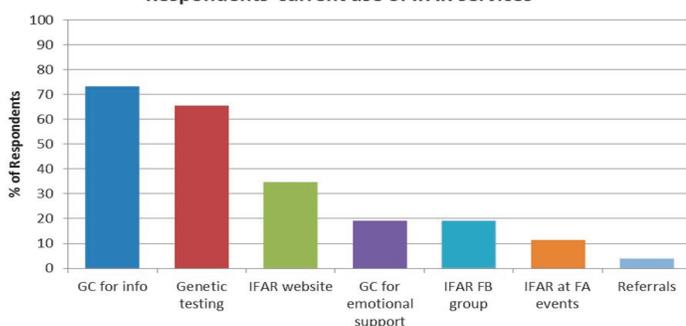
Respondents' comprehensive motivations for participation in the IFAR



## IFAR Services Used

Survey respondents were asked to comment on their use of IFAR services (see graph for a complete list of IFAR services). Contact with an IFAR genetic counseling for information and research genetic testing were identified as services used by most survey respondents. These were also identified by respondents as the most helpful current IFAR services. Thirty-seven percent of survey respondents are “friends” with

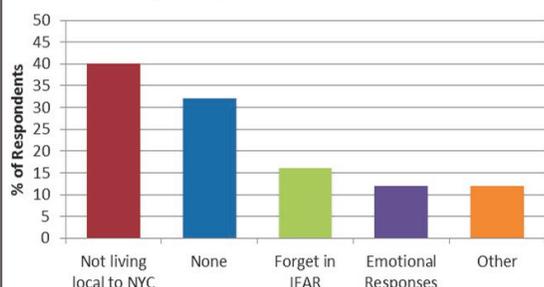
Respondents' current use of IFAR services



the IFAR (Agata Smogorzewska) on Facebook. Those who are FB friends with the IFAR think it's a useful way to easily contact and keep up-to-date with the IFAR, especially through the private

messaging function. Many survey respondents who have not connected with the IFAR in this way did not know that the IFAR had a FB account (77%).

Respondents' challenges in continued participation in the IFAR



## Challenges to IFAR Participation

The most common challenge to continued participation in the IFAR was not living local to New York City (40%). Many respondents had similar feelings to this IFAR participant, who asked for:

*“more outreach to those of us who are not geographically close”*

Some international participants stressed that it was a significant challenge in IFAR participation. Another perceived challenge to participation was respondents often forget that they are a member of the IFAR (16%). This speaks to the need for more interactive resources and communication between the IFAR and its participants.

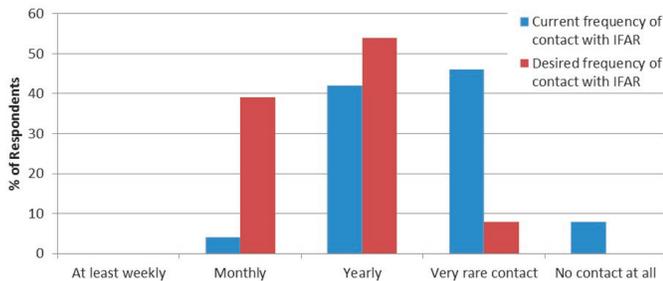
# Communication with the IFAR and Participant Satisfaction

Most participants who responded to the survey wanted more communication with the IFAR than they are currently receiving. Most respondents are receiving very rare or yearly contact, but would like yearly or monthly contact. In general,

Only 32% of respondents classified their understanding of what the IFAR does as “full”, while most (68%) respondents said they have “partial” understanding. This speaks to a need for more communication through updates to participants about ongoing IFAR research.

It is important to us that participants are satisfied with their involvement in the IFAR, and we want to address participant issues as they arise. We are pleased to learn that most respondents (79%) see their participation in the IFAR as a positive experience and meaningful (89%) for themselves or their families. We recognize that 21% of respondents feel that they have received what they needed from the IFAR up to this point. While we did not directly ask what respondents are referring to, we believe that one factor may be that many families are waiting on desired research genetic test results. We thank you for your patience and encourage you to contact us at any time to ask about the status of your testing.

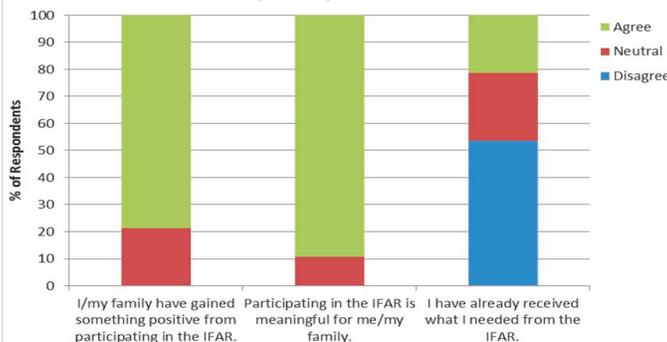
**Respondents' views on frequency of communication with the IFAR**



respondents said that the most important reasons for the IFAR to contact participants are:

- 1) To give general IFAR research updates;
- 2) To give information about a family’s genetic testing status;
- 3) To remind families to give medical updates or other information to the IFAR.

**Respondents' current feelings about the value of participation**



**How could participation in the IFAR be made easier?:**

*“more communications on new developments to families”*

- An IFAR Participant

*“I am not aware of what I can do to contribute to IFAR. More information about what it does would be helpful.”*

- An IFAR Participant

## Let us know how you and your family are doing!

We always look forward to hearing from you. Here are ways to keep us updated on you and your family, and to contact us if you need anything from the IFAR:



**Facebook:** “Friend” us by searching **fanconianemiaregistry** or **Agata Smogorzewska**. We like to see your posts and pictures! This way, you’ll have easy access to posted links to ongoing projects and, if you’d like, we can use the private messaging function to make communication more convenient.



**E-mail:** Contact the IFAR genetic counselors by e-mailing Jennifer Kennedy at **jkennedy@rockefeller.edu** or Erica Sanborn at **esanborn@rockefeller.edu**. You can also contact the IFAR’s Principal Investigator, Dr. Agata Smogorzewska at **asmogorzewska@rockefeller.edu**



**Website:** <http://lab.rockefeller.edu/smogorzewska/families>  
Here you can find general information about FA, information about ongoing projects, and most importantly, our electronic medical update form.

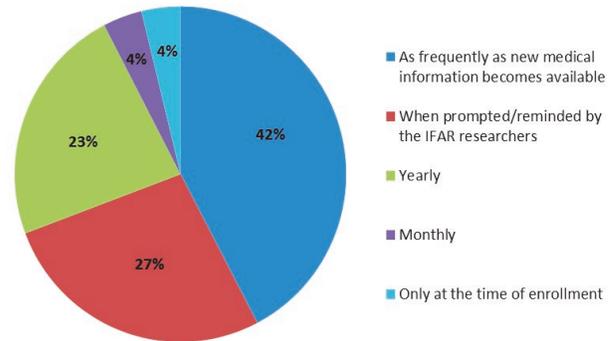
The collection of medical information through a participant's life is very important in the type of research performed through the IFAR, and helps to increase our general knowledge of FA. Historically, we have asked for your medical information through your doctors. We are interested in expanding the ways we collect medical information, which includes having participants directly report their own medical information to the IFAR. When asked what participants thought of this idea, 100% of survey respondents said that they were interested in directly reporting med-

ical information to the IFAR about themselves and their families. The first step to including data that you provide into the IFAR system is to do a pilot project, comparing the information you may provide, to the information your/ your child's doctor may provide, and to the medical records that we obtain on you/ your child. Most (85%) of respondents said they would be interested in being a part of this pilot project. Most respondents said they would prefer to enter medical information into a secure internet form. Visit the IFAR's website for updates about this project.

*"I would be willing to do anything that can impact the future care and treatment of anyone with FA. I think that parents have different input than doctors, resulting in very important information to obtain."*

- An IFAR Participant

Desired frequency of providing medical information

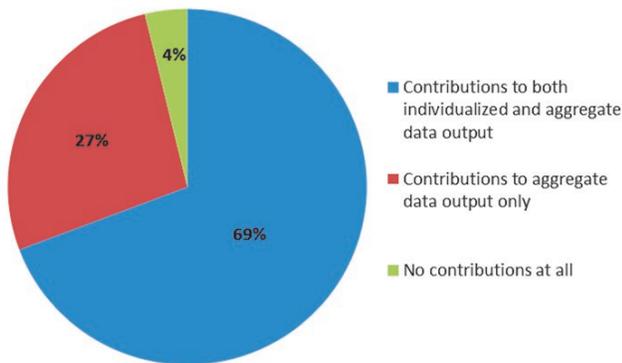


What improvements could be made to the IFAR?:

*"Making it easily accessible for FA researchers worldwide"*

- An IFAR Participant

Willingness to contribute de-identified data for aggregate and individualized output



## Future Project: Interactive IFAR Database

The information that participants provide to the IFAR is entered into a database to organize it for our researchers. Our goal is to eventually create an interactive database, where IFAR participants can log in and have access to de-identified information about the entire group of participants in the

IFAR. De-identified information includes medical information about a participant without his or her name, date of birth, residence, and other unique information that may identify the individual. "Aggregate" information output is when trends are reported, taking into consideration information from an entire group of people. An example of this is the observed trend that 60% of individuals with FA are in complementation group FA-A. Individualized information output is when a participant's medical record can be viewed as a whole, with no identifying information. For example, you could see that an individual was diagnosed with

FA at age 5, and that same individual is of complementation group FA-A. Most survey respondents (96.2%) would be willing to have their family's information as part of an aggregate and/or individualized data output to other IFAR participants and external researchers. Also, most participants are interested in viewing aggregate clinical and genetic information, and want the opportunity to submit questions to IFAR researchers for aggregate analysis. The IFAR is working to develop this service to share the information we've collected over the years to researchers and participants.