

Privacy Policy

Our privacy policy is as follows:

Releasing Information to Others

1. We will not release your name, address or other information to other parents, medical professionals or researchers unless you have given us your permission to do so.
2. We will not release your name to anyone whose purpose, in our opinion, is to raise money or to sell you something.
3. From time to time we may release or publish anecdotes, summaries or data analyses. When we do this we will portray the data in such a way that individuals or specific cases are not recognizable. Any exceptions to this will be on a case-by-case basis only after obtaining permission from the family involved for that specific item.

Fowarding Information

4. From time to time, we will forward to you things from researchers or other organizations. While our forwarding of these items does not necessarily constitute our endorsement, we will only forward things that might be of interest.
5. We won't forward information from anyone whose purpose, in our opinion, is to raise money or to sell you something.
6. If we share other family names, addresses and phone numbers with you (at your request and with the permission of the family) you are not authorized to further forward this information except for family networking or legitimate medical research.
7. Although we will be careful to whom we release information, we are not responsible for its subsequent use by the recipient.

Your Responsibilities

8. If you submit items for our family stories or other public parts of our websites, you acknowledge that you are releasing it for all the world to see and that we are not responsible for how the general public may use that information.

Adopted 31 March 2000