



Code of Conduct For Advocacy

All participants at our NC Rare Disease Day are asked to adopt and adhere to these guidelines.

1. I am attending our NC Rare Disease Day to learn, share information, and advocate on behalf of the rare disorders community. In that spirit, I recognize that I might be part of discussions that include disclosure of an individual's personal information (e.g., health or financial information). I will keep anything that I hear confidential and will not discuss it outside of the event.
2. As a consumer and member of the rare disorders community, I agree to help protect the integrity of NC Rare Disease Day as an opportunity for the rare disorder community to come together and advocate for their needs. While I recognize that some consumer participants have a commercial interest in the supply of products and/or services to the rare disorder community, to protect the spirit of the event, I will not attempt to approach a representative of the healthcare industry to gather information about their company's products and/or services while attending this event. I may, however, request their contact information/business card and contact them after the event has concluded.
3. If, along with being a patient, caregiver, family member, or healthcare provider, I have a commercial interest in the supply of products (e.g., am employed by a home care company, drug manufacturer, or other similar organization) or services related to patient care, I agree to the following:
 - a. I will refrain from using consumer participants' information I specifically and exclusively learn at this event, which I would not have otherwise have had access to without attending this event, to promote my company's/organization's products and/or services. My relationships at this event will be strictly as consumer to consumer; and
 - b. I will refrain from steering conversation in the direction of rare disorders business. If I am asked directly about my company's/organization's products and/or services, I will state that this educational event is not the place for me to discuss any commercial interests.