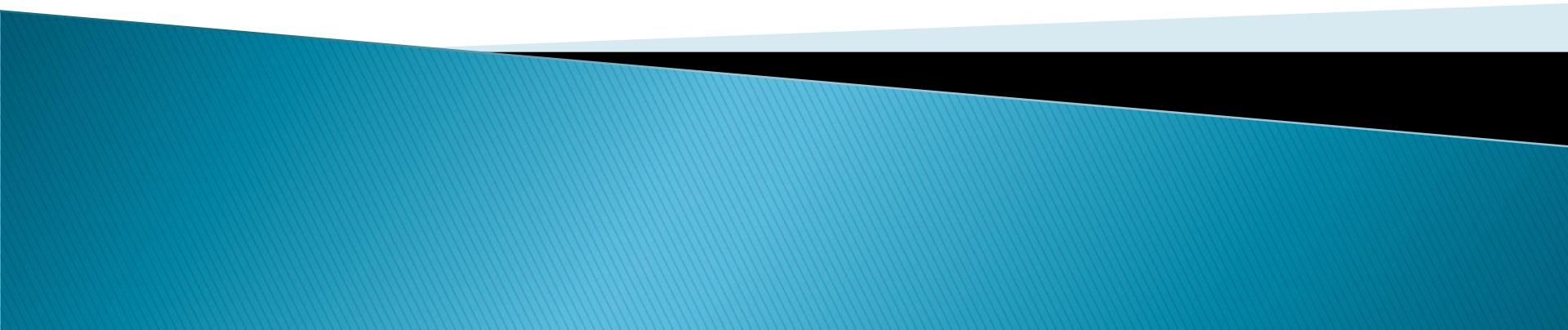


# Social Media Strategy

For Rare Disease Patient Groups



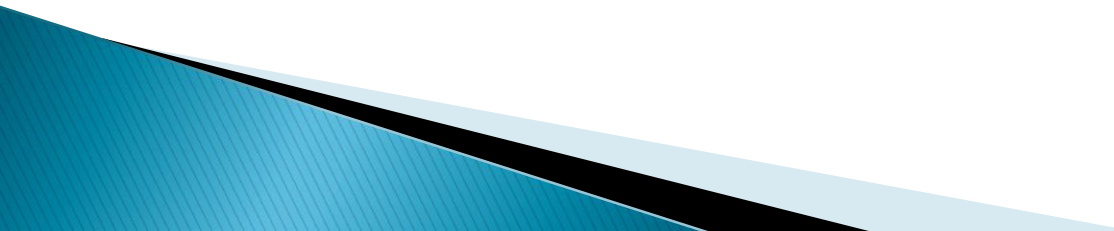
# Social media is not free

- ▶ Requires investment of patient group to train volunteers
- ▶ Include social media into overall communications strategy – coordination
- ▶ Costs volunteers time

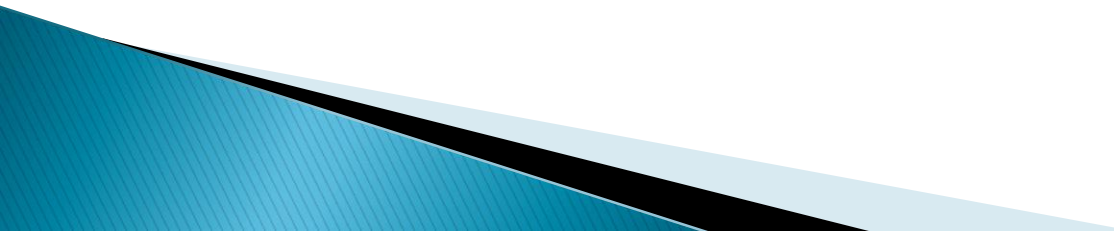
Make a basic plan with your group.



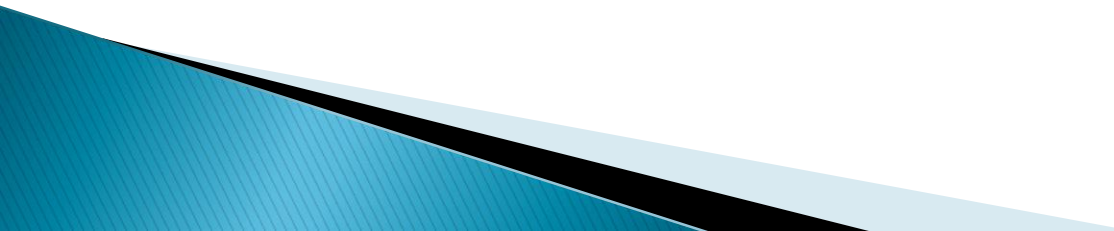
# Social media

- ▶ Two way conversation – telephone, not megaphone
  - ▶ Digital tools that enable conversation
  - ▶ Facebook is the pub
  - ▶ Twitter is the party
  - ▶ Blog is digital magazine
  - ▶ Flickr is photo gallery
- 

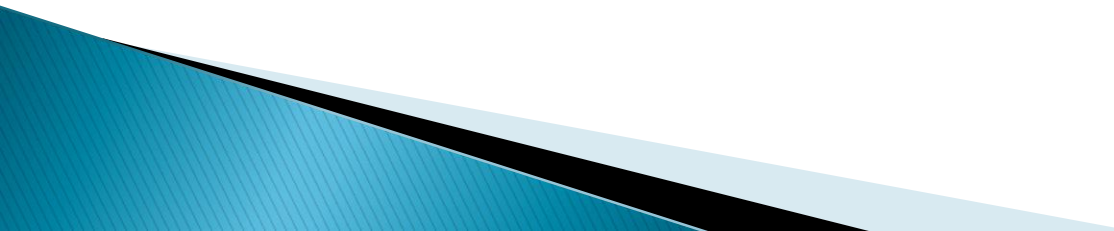
# When developing a Social Media Strategy...

- Roles- you need volunteers who understand your group's mission
  - Topics- you need to think ahead to provide content and stay up to date on current developments
  - Privacy- you need to protect your members while remaining flexible
  - Responding to comments- prepare
- 

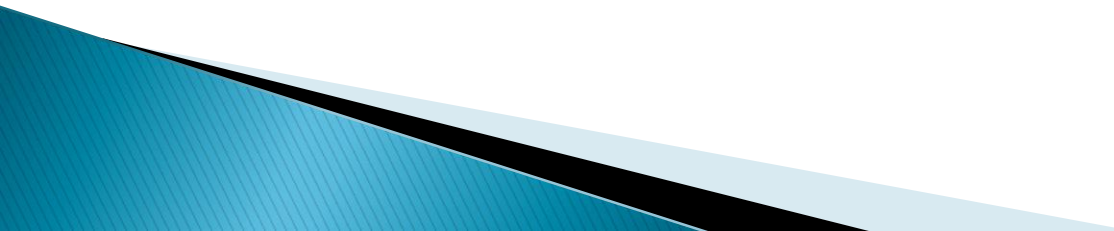
# Roles

- Who is responsible for social media?
  - Who is coordinating between groups? Monitoring other groups?
  - Who is allowed to post to each channel?
  - Who is contributing information to be posted?
- 

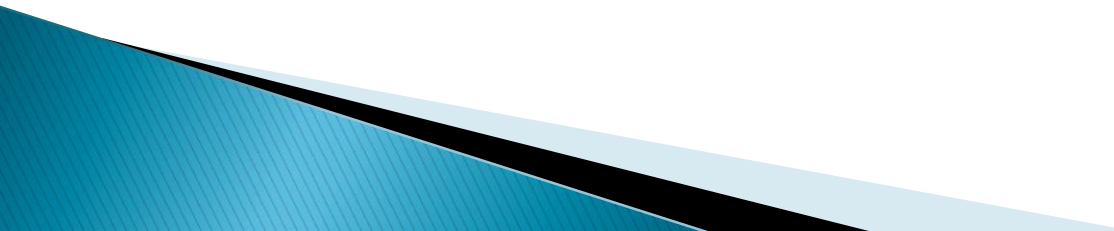
# Topics

- Awareness to general public, fundraising
  - Research and scientific updates
  - Treatments and clinical trials
  - Events, workshops, conferences, online webinars
  - Physicians and specialists working in the field
  - Situations in other countries, supporting new patient groups forming
- 

# Topics cont.

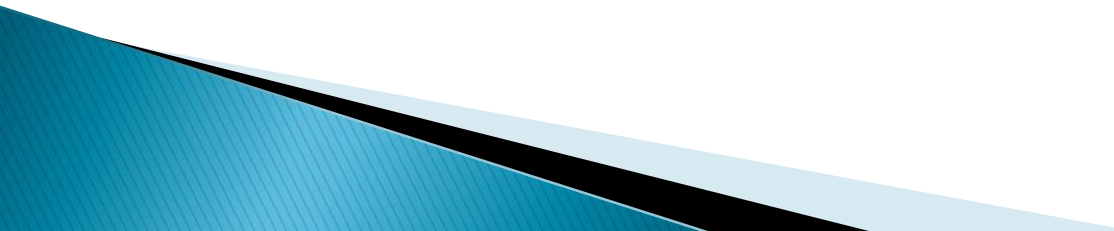
- What topics should not be discussed?
  - What topics require approval or consensus before posting?
- 

# Privacy

- Who can join the group or see the page?
  - Do you screen members? Does that prevent legitimate members from joining?
  - Do you allow photos of kids or adults to be shared?
  - Copyright materials or scientific articles to be shared without permission?
  - How do you protect privacy?
- 



# Responding to comments

- How will you respond to a negative or misinformed comment?
  - Have a plan in place, don't just delete the comment, it can be an opportunity to clear up a misunderstanding or clarify your role as a patient group.
- 

# Links

E-patients White Paper: [http://e-patients.net/e-Patients\\_White\\_Paper.pdf](http://e-patients.net/e-Patients_White_Paper.pdf)

Social Media Decision Guide

<http://www.idealware.org/reports/nonprofit-social-media-decision-guide>

Guardian Article on Health Social Networks in US

<http://www.guardian.co.uk/healthcare-network/2011/nov/08/us-healthcare-viral-social-networks>