

SURVEY

The NCFAC is interested in helping to serve the CF community better. Please let us know how you feel we can do this. All questions are optional.

Name: _____

Address: _____

Phone: _____ E-mail: _____

Connection to CF (i.e. patients, parent, caregiver, family member, etc.): _____

Care Center or CF Doctor: _____

1. Do you feel the general public is largely unknowledgeable about CF? _____ Yes _____ No
Comments: _____

2. Of the following groups, which do you think needs to be educated the most of about CF? (Rank in order with #1 needing most and #5 needing least.)

_____ Schools _____ Family _____ General Public

_____ Workplaces _____ Friends

3. Do you feel more awareness will help to improve your quality of life by helping others to understand effects of CF? _____ Yes _____ No _____ No Difference
Comments: _____

4. Do you feel that by increasing CF awareness that fundraisers for research will benefit by increased contributions? _____ Yes _____ No _____ No Difference
Comments: _____

5. Do you have any ideas that you might share that would increase awareness? _____

6. What is your primary source of information on CF? (Medical, Educational, & Supportive)

_____ Doctor _____ Social Worker _____ Internet

_____ Printed Materials _____ Support Group _____ Other Individuals

_____ Other _____

7. What resources have you needed that you have either been unable to find or has not been easily Accessible? (Check as many that apply.)

_____ Medical Information _____ Educational Materials

_____ Financial Information _____ Emotional Support

_____ Practical Information on Daily Care _____ Other _____

8. What are your greatest needs in the educational area? (check all that apply)
- | | |
|--|---|
| <input type="checkbox"/> Updated Materials | <input type="checkbox"/> Access to Latest Studies/Research |
| <input type="checkbox"/> Knowing where to find materials | <input type="checkbox"/> Career Counseling |
| <input type="checkbox"/> Information on Dealing With School Officials/Teachers | <input type="checkbox"/> Practical Information on Managing & Living with CF |
| <input type="checkbox"/> Information Dealing With College & the Workplace | <input type="checkbox"/> Other _____ |

9. What is the approximate distance to your CF care center/CF doctor?
- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Less than 10 Miles | <input type="checkbox"/> 50-100 Miles |
| <input type="checkbox"/> 10-50 Miles | <input type="checkbox"/> 100+ Miles |

10. Do you have internet access?
- | | |
|-------------------------------|---|
| <input type="checkbox"/> None | <input type="checkbox"/> Public Library |
| <input type="checkbox"/> Home | <input type="checkbox"/> Other |
| <input type="checkbox"/> Work | |

11. What do you feel are the greatest needs in the area of support? (check all that apply)
- Support Group Information - Where to find one, how to begin one, networking/idea exchanging with other groups.
- Benefits Counseling - Information on Medicaid, Medicare, private insurance, state programs, SS Disability, SSI, etc.
- New Diagnosis Intervention – Practical information, contact information, and emotional support.
- Information on locating drug assistance programs and/or equipment.
- Network of volunteer CF patients and family members who would be contacts for emotional support.
- Help in locating or obtaining professional crisis counseling.
- Reviews on available products including equipment (nebulizers, cpt equipment) and other products (nutritional supplements, shower coverings for PICC lines, etc.)
- Director of newsletters, support groups, and other CF organizations.

**Please mail completed surveys to: NCFAC
406 Harrison
Sikeston, MO 63801**