FEATURE ARTICLE

Parent and Child Perceptions of the Benefits of Research Participation

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Table 1.
Child and Parent Demographics

Variable	*n (%); or mean (SD), range*
Child's age	12.56 (2.82), 8-17
Parent's age	42.26 (7.23), 27-65
Child's sex: female	93 (52%)
Parent sex: female	166 (92%)
Child's race	
black or African American	60 (33%)
Asian	3 (2%)
white	106 (59%)
other	10 (6%)
missing	1 (1%)
Is the child Hispanic or Latino?	
no	172 (95%)
yes	7 (4%)
missing	1 (1%)
Income	
less than $19,999	26 (14%)
$20,000-$39,999	33 (18%)
$40,000-$59,999	19 (11%)
$60,000-$79,999	12 (7%)
$80,000-$99,999	18 (10%)
more than $100,000	55 (31%)
prefer not to answer	17 (9%)
Parent education	
some high school	8 (4%)
completed high school	36 (20%)
some college or technical school after high school	47 (26%)
college graduate	49 (27%)
some postcollege graduate education	10 (6%)
master's, PhD, MD, law degree	30 (17%)
Family structure	
two parents	116 (64%)
two parents, stepfamily	10 (6%)
single parent	54 (30%)

Table 2.
Protocol Details for Enrolled Participants (n = 180)

Division	*n (%)*
allergy/immunology	17 (9%)
cardiology	9 (5%)
endocrinology	7 (4%)
gastroenterology, hepatology, & nutrition	18 (10%)
general pediatrics	58 (32%)
hematology	4 (2%)
nephrology	3 (2%)
neurology	6 (3%)
oncology	1 (1%)
orthopedic surgery	5 (3%)
pulmonary	23 (13%)
radiology	1 (1%)
rheumatology	28 (16%)
Is the study interventional or observational?	
interventional	44 (24%)
observational	136 (76%)
For interventional studies only:	
allocation	
single arm	6 (14%)
randomized controlled trial	37 (84%)
nonrandomized trial	1 (2%)
Risk category	
minimal	147 (82%)
minor increase over minimal	27 (15%)
greater than minimal	6 (3%)

Appendix.
Examples of Responses to Open-ended Item about Potential Benefits

	Parent responses	*Child responses*
Direct health benefit	"Would like to see it cured but just to help it not get any worse."	"Improve lung functioning; get mucous out of my lungs" (age 17).
	"Cured of peanut allergy."	"I have a bleeding problem and they might be able to fix it" (age 11).
Future health benefit	"In the global sense of health, whenever you do research, treatments may be improved and benefit you in the future."	"Maybe they will find better treatments that will directly benefit me in the future" (age 13).
	"General research at the hospital could eventually help your child."	"Possibly in the future by helping doctors find a cure" (age 17).
Improve understanding of the condition	"Better understanding of his condition."	"Because then I could learn more information about asthma" (age 11).
Quality of life	"Quality of life."	"I will be able to sit at any part of the table at lunch at school, because I won't be allergic anymore" (age 8).
Help others	"They could end up finding a diagnosis or treatment that could be beneficial to a lot of people."	"Help other children" (age 9).
Contribute to medical knowledge	"Increased knowledge."	"'Cause it could teach the doctor something, help them figure out stuff" (age 11).
		"Help researchers figure out the best way to do it" (age 13).
Emotional benefit	"Helping her feel like she is doing something positive with a condition she didn't choose to have."	"Help me be more active, bring mood back to where it was before I got sick" (age 17).
Find out if or why the child has the condition	"Can find out why she bleeds."	"If they get more tests done they could probably find out what causes it" (age 14).
Monitor the child's health	"It will keep me up to date about her health."	"Can monitor your health" (age 17).
Access to new, better, or more thorough treatments	"Having an extra set of eyes, more thorough, longer echo."	N/A