

Supplemental Table 1. SFS eligibility criteria

Inclusion criteria:

- Males or females age at least 18 years at the time of entry
- Diagnosis of alpha-1 antitrypsin deficiency
- Participant in AlphaNet program because of prescription for alpha-1 antitrypsin augmentation therapy
- Evidence of pulmonary disease with one or more of the following:
 - FEV1 less than 80% predicted and FEV1/FVC less than 0.70
 - Emphysema on a previous CT scan of the chest
 - Receiving augmentation therapy for lung disease
- Accessible by telephone
- Ability and willingness to complete monthly and semi-annual questionnaires by telephone interview
- Ability and willingness to provide informed consent

Exclusion criteria:

- Participating in other studies that involve some type of intervention
- Unable or unwilling to perform physical exercise lasting a minimum of 20 minutes, three times a week and that includes exercise of both upper and lower extremities
- Individuals with self-reported coronary or cardiovascular disease or insulin-dependent diabetes whose health could be put at risk by a self-monitored exercise or nutrition program. Such individuals could be enrolled if their personal physician certified in writing their medical suitability.
- Has received a lung transplant or is expecting or planning to receive a lung transplant within two years of study initiation
- Females who are pregnant or expect to become pregnant within three years of study initiation

SFS- Step Forward Study; FEV1- Forced expiratory volume in one second; FVC- Forced vital capacity; CT- Computerized tomography;

Supplemental Table 2. Mailings to SFS participants

Date	Materials	Intervention Group	Standard Care Group
10/2009	Exercise guide, pedometers, daily diaries, and breathlessness self-assessment guide	X	X
10/2009 - Intervention 1	Therabands, exercise poster with theraband instructions	X	
01/2010	Healthy Eating in COPD booklet	X	X
07/2010	Harmonica with instructions for breathing exercise	X	X
07/2010- Intervention 2	Small group diet and nutrition consultations with a registered dietician (individualized by low, normal, high BMI) with follow-up 3 months after initial consultation	X	
02/2011	Water bottle with hydration recommendations	X	X
02/2011- Intervention 3	“Breathing techniques in Alpha-1” video	X	
03/2011	SFS Sweepstakes (award drawing for those with best diary adherence)	X	X
07/2011- Intervention 4	Exercise physiology and use of supplemental oxygen lecture by teleconference or audio recording	X	
02/2012	Alpha-1 Family Cookbook	X	X
02/2012- Intervention 5	Weight training using soup cans including exercise poster. Exercise ball and poster on its use.	X	
07/2012- Intervention 6	Exercise peddler and instructions.	X	
04/2013	Oximeter with instructions and results table	X	X
04/2013- Intervention 7	“Virtual Pulmonary Rehab” (VPR) including videos, teleconferences, and written materials over 12-week period	X	

Note: Shaded rows represent mailings to the intervention group only; not shaded rows represent paired mailings (mailed to both standard care and intervention group) to maintain blinding

Supplemental Table 3. Comparison of baseline characteristics of patients included in analyses to patients excluded due to missing data, n=500

	Included	Excluded	p-value
	N=429	N=71^a	
Age, years, mean (SD)	57.80 (9.24)	56.94 (9.03)	0.55
Female, n (%)	224 (52.21)	36 (52.94)	0.95
Non-Hispanic White, n (%)	422 (98.60)	67 (98.53)	0.82
Married, n (%)	311 (73.35)	41 (60.30)	0.03
ZZ variant, n (%)	348 (88.55)	53 (89.83)	0.29
Smoking history, n (%)	315 (75.18)	50 (73.5)	0.79
Oxygen use, n (%)	226 (52.68)	32 (45.1)	0.23
Body Mass Index, n (%)	<i>(included n=422)</i>	<i>(excluded n=78)</i>	0.89
Low (≤ 19)	19 (4.50)	4 (5.13)	
Normal (20-25)	184 (43.60)	33 (42.31)	
High (>25-30)	140 (33.18)	23 (29.49)	
Very High (≥ 30)	79 (18.72)	17 (21.79)	

^a Note: of the n=71 excluded from the analyses, n=32 were from the intervention group and n=39 from the standard care group;

Supplemental Figure 1. AlphaNet's Weekly Food and Activity Diary

AlphaNet's Weekly Food & Activity Diary

Name: _____

1. Week Starting (date): ____/____/____

2. What is your current weight (lbs)? _____

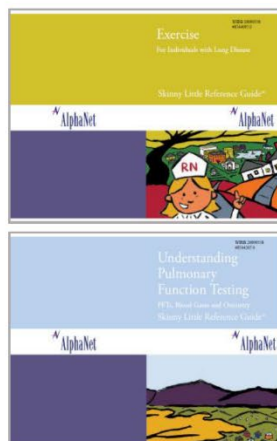
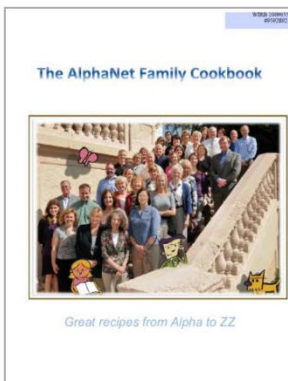
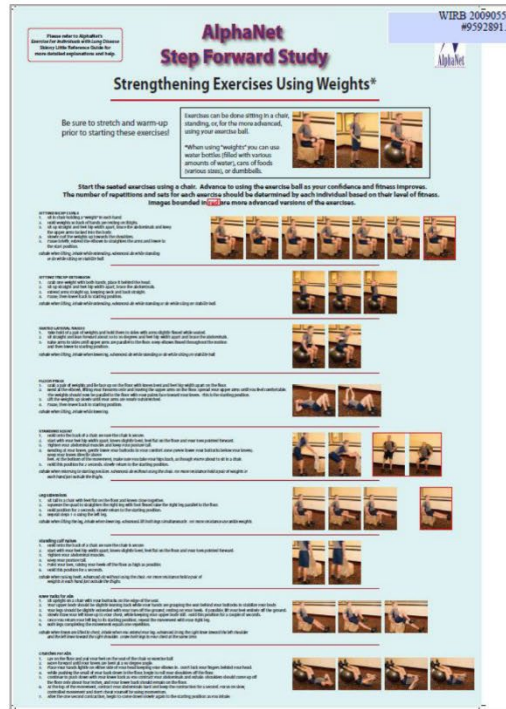


Day of the Week	Length of Activity Time (Minutes)			Pedometer Reading*	Breakfast Size		Lunch Size		Dinner Size		Additional Meals**
	Warm-Up	Strength	Cardio		None	Small	None	Small	None	Small	
Monday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Tuesday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Wednesday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Thursday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Friday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Saturday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	
Sunday					<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	<input type="checkbox"/> None <input type="checkbox"/> Medium	<input type="checkbox"/> Small <input type="checkbox"/> Large	

* Recorded from Pedometer (# is in Steps)

**Enter number of additional meals. Leave blank if none.

Supplemental Figure 2. Pictures of selected mailings to SFS participants



Supplemental Figure 3. "Virtual Pulmonary Rehab" (continued)

The figure displays 12 virtual pulmonary rehab program session cards, arranged in a 4x3 grid. Each card is titled "Virtual Pulmonary Rehab Program" and includes a session title, a brief description, a list of information included, and a list of tools included. The sessions are:

- Session One: Here We Go!** Measuring Our Baseline and Laying the Groundwork. Information includes: Monitoring Oxygen Saturations, Fitness Assessments, Monitoring Exercise Intensity, and Optimal Times to Exercise. Tools include: RPE/RPD Scales, Fitness Assessment Score Card, and Movement Worksheet.
- Session Two: The Foundation:** Pursed lip breathing, Warm-ups & Cool-downs. Information includes: Pursed lip breathing (PILB), Warming Up, Cooling Down, and Flexibility. Tools include: Warm-up Routine, Cool-down Routine, and Home Exercise Programs.
- Session Three: Follow the Leader:** Resistance Training with Basic Moves. Information includes: Warming Up, Resistance Training (RT), and Cooling Down. Tools include: Warm-up Routine, Resistance Training (Strength) Routine, and Cool-down Routine.
- Session Four: Prescribing Movement as Medicine:** Exercise in Balanced, Effective Doses. Information includes: The Fitness Tripod, The FITT Prescription, Exercise Options, and Keeping Exercise Safe. Tools include: Home Exercise Programs.
- Session Five: Making Life a Moving Experience:** Activities of Daily Living (ADLs), Pacing, & Energy Conservation. Information includes: Activities of Daily Living, Recovery Breathing, Pacing & Energy Conservation, Posture Training, Bending & Lifting, and Coordinating PILB with Common ADLs. Tools include: Home Exercise Programs.
- Session Six: The Guiding Light of Pulse Oximeters:** Measuring and Maintaining Oxygen Saturations. Information includes: Oximeter, Oxygen Saturations (SpO₂), Your Pulse Oximeter, Managing Abnormal PR/SpO₂, and Oxygenation. Tools include: Oximeter, SpO₂/PR - Log, and Home Exercise Program.
- Session Seven: Performance Enhancements:** Strategies for Managing Your Exercise Routine. Information includes: Managing an Exercise Routine, Exercise & Nutrition, Inhaled Medications, Resuming Exercise, Scheduling Exercise, Medications, and Home Exercise Programs. Tools include: Home Exercise Programs.
- Session Eight: Assessment and Planning:** Self-Management Strategies. Information includes: Symptoms, Infection Prevention, Defining the Problem, Contact the Doctor, Breathing Recovery DVD Demo, Tracking Tool, and Home Exercise. Tools include: Home Exercise.
- Session Nine: Fueling the Fire:** Healthy Diet and Managing Body Composition. Information includes: Eating for Energy, Exercise & Body Composition, Nutritional Challenges, ChooseMyPlate, and Home Exercise Programs. Tools include: Home Exercise Programs.
- Session Ten: Taking Charge:** Controlling Stress, Breathing and Exercise. Information includes: Stress, Managing Stress, Exercise, Energy for Favorite Activities, Coordinating Breathing with Daily Tasks, Worksheets, and Home Exercise Programs. Tools include: Home Exercise Programs.
- Session Eleven: Taking the Show on the Road:** Strategies for Leisure, Recreation and Travel. Information includes: General Guidelines, Considerations, MD Travel-Specific Appointment, The Journey, and Tracking Tools. Tools include: Home Exercise Programs.
- Session Twelve: Here We Are!** Measuring Our Progress, and Staying on Track. Information includes: Review: Fitness Assessments, Adherence Factors, Motivational Strategies, and Claiming Your Inner Champion. Tools include: RPE/RPD Scales, Fitness Assessment Score Card, and Movement Worksheet.

