Coordinator
GUIDEBOOK

Fistula Coaching Program
Preface

The Renal Network, Inc. wants to work with you to strengthen your patient fistula education program. The *Fistula Coaching Program* is a peer-to-peer coaching program that involves patients helping patients through positive communication, support in the planning and decision-making process. The Network Patient Leadership Committee was instrumental in its development.

We invite you to read both the Fistula Coaching Program *Coordinator Guidebook* and the *Patient Coach Handbook* and then to choose and train qualified patients to provide peer support and education to other patients who are hesitant about fistula placement. We encourage you to use the tools and materials selected for this program.

The Network Patient Services Department staff can help you in the development of your program if you need assistance. We encourage you to provide feedback on how you make use of the program and assist us by identifying its benefits as well as its weaknesses. Thank you in advance for your support of this program and for your feedback. We welcome the opportunity to work together in any aspect of the Fistula Coaching Program.
INTRODUCTION

The Fistula Coaching Program is designed to promote patient selection of the best vascular access choice through peer-to-peer education.

This facility-based program calls for the selection and training of patient volunteers to be active Fistula Patient Coaches. The role of the patient coach is to be available to patients who want to know more about having a fistula from someone who has been through the decision making process and has a healthy, mature and functional AV fistula. The patient coach can be trained to provide educational resources and support to the interested or hesitant patient contemplating an AV fistula.

To facilitate the implementation of the program two booklets were created:

- The Fistula Coaching Program Coordinator Guidebook, which outlines points for the facility to consider when it develops its training program.
- The Fistula Coaching Program Patient Coach Handbook, which provides tips and resources for the patient volunteer and can act as a workbook for the Coordinator to use in the training program.

The Fistula Coaching Program, developed by The Renal Network and its Patient Leadership Committee, is one resource to assist facilities with promoting fistula placement and overcoming barriers to AV fistula placement.

Feel free to reproduce the Patient Coach Handbook or any of the Network resources provided to use as part of your facility Fistula Coaching Program. The complete program is available on a CD-ROM or online at http://www.therenalnetwork.org/services/FFcoach.php. To obtain additional printed copies or to order a CD-ROM, please use the order form available in Appendix D.
FISTULA COACHING PROGRAM

The Fistula Coaching Program requires that a facility staff member, usually the Vascular Access Coordinator or the facility Social Worker, oversees and coordinates the activities of the patient coaches. Program Coordinators are responsible for training patient coaches and for making sure the patient coaches are following the policies and procedures of the facility. The *Patient Coach Handbook* may assist you in developing your facility Fistula Coaching Program. It provides information about what the coach does and does not do, provides suggestions on ways to approach patients who are in various stages of being interested in a fistula, provides communication and problem-solving tips, and discusses confidentiality.

COORDINATOR RESPONSIBILITIES

**Determine Selection Criteria for the Patient Coach**

When starting a new Fistula Coaching Program, it is important to have a well-defined idea of the right person for the job. Consider the following characteristics as you establish your selection criteria:

**A. Hemodialysis status**

- Copes well with kidney failure
- Has a working fistula
- Is fairly compliant
- Understands how to care for a fistula

**B. Helping skills**

- Wants to share this experience and knowledge to help fellow patients improve their quality of life
- Enjoys talking to others
- Accepts other points of view
- Respects others
- Knows and accepts that every situation will be different with each patient
- Has good listening and communication skills
Determine the Responsibilities of the Fistula Patient Coach

You may know in general what role you want the patient coach to fill and what you want them to do. Often the little details and the actual tasks required of the role may be difficult to come up with at first. This is an area, however, where it is better to be comprehensive as a way of maintaining good boundaries. The following are some suggested “do’s” and “don’ts”:

A. What the patient coach does:

- Visit the patient
- Listen attentively
- Provide appropriate resources
- Help with problem solving
- Encourage the patient to talk to his or her doctor, to a vascular surgeon, and the health care team about fistula concerns
- Provide emotional support for whatever decision the patient makes regarding fistula placement

B. What the patient coach does not do:

- Offer personal opinion
- Provide medical advice
- Compare his/her medical history to that of the patient
- Gossip about the unit staff, another patient, or patient family member
- Tell the patient what to do or not to do
- Pressure the patient in any way
- Get angry if the person decides not to get a fistula
- Make the patient feel bad or guilty if he/she decides against a fistula

Facilitate the Patient Coach Recruitment

Once the responsibilities of the patient coach have been established, shape your recruitment strategies to attract the best candidates. The following are some approaches to consider.

- Identify patients who are good role models; observe interactions with patients and staff members. Extend personal invitations to potential candidates.
- Promote the positive aspects of being a Fistula Patient Coach, such as mentoring and service.
• Involve former and current patient volunteers in the identification and recruitment process.

• To promote self-selection, consider posting recruitment information for patient coach volunteer positions.

**Organize the Patient Coach Training Program**

• Arrange training in small groups or one-on-one.

• Use the *Patient Coach Handbook* as your training tool.
  (Appendix E)

• Provide resources for the patient coach to share with patients. (Appendix A)

• Include facility guidelines on issues such as confidentiality and harassment.

• Provide a volunteer agreement form which includes reasons for release from program.

• Create a model for your peer-to-peer education program using one or more components, such as, one-to-one, special presentations or events, and regularly scheduled pre- or post-dialysis waiting room Q&A sessions.

• Provide overview of program supervision:
  o Assign coaching responsibilities.
  o Assign one-on-one coaching responsibilities from among patients requesting assistance from coaching program and granting permission for peer-to-peer coaching. You may use the *Vascular Access – Making Your Lifeline Choice* as a tool to match patients with a coach. (Appendix B)
  o Review areas/topics that the coach is free to address and discuss with the individual patient assigned.
  o Schedule meetings with the patient coach on a regular basis.

• Recognize the patient coach’s efforts periodically through luncheons, bulletin boards, or small gifts.

• Evaluate and determine if the program seems to be beneficial to patients in your unit. Use the form provided in Appendix C for program feedback.
Appendix A

Patient Coach Resources

Access Care: Your Lifeline - Provides information about vascular access. Included are tips on how to care for the access, problems that can develop and how to prevent them, and treatment options if a problem persists. (Revised edition)

Arterial Venous Fistula (AVF) - Provides general information gathered through a collaborative effort of Patient Services Coordinators from the 18 ESRD Networks across the nation.

Choosing Your Vascular Access - Provides information on the risks of catheters and the benefits of fistulas.

Ease the Ouch: Taking the fear out of AV Fistula Placement - This brochure is a discussion guide for patients, family members and healthcare staff to use when learning/informing people about fistula placement and managing fear.

Fistula First Patient Resources – A list of available resources compiled by FistulaFirst.org.

Renal Outreach – Reprints of articles featured in the Network patient newsletter:

- Frequently Asked Questions - AVF
- How Do I Look
- Naked Arm
- One-site-It is

Vascular Access – A collection of video shorts created by members of the Patient Leadership Committee available on DVD which outlines the benefits of AVF through the personal experiences of both patients and staff members.
Appendix B

Vascular Access – Making Your Lifeline Choice

A kidney patient’s choice of vascular access is one of the most important choices he or she will make while on dialysis. More evidence has emerged concluding that the AV fistula is the most effective and complication free access choice.

Has your nephrologist/staff talked to you about having an AV fistula placement? (Please circle your answer.) Yes No

Have you ever refused AV fistula placement? (Please circle your answer.) Yes No

If you have refused AV fistula placement, what factors affected your decision to refuse an AV fistula placement? (Please check all that apply.)

___Afraid of the big needles
___I’m too old
___Potential fistula problems – like excessive bleeding after treatment
___Don’t trust staff to stick me
___Don’t want another surgery
___Don’t have time to stay and hold site after treatment
___Can get on/off treatment easily with catheter
___Doctor told me I can’t have one because (please specify) ______________________
___My access is my choice
___Scared of pain
___Patients with fistula don’t recommend it
___Won’t make a big difference in my outcomes, numbers
___Staff hasn’t encouraged it
___Catheter is less noticeable
___AV fistula takes too much care
___Catheter is easier to maintain

___Don’t know enough about AV fistula to make a decision
___Don’t want a scar
___Don’t want to be stuck
___Generally afraid of having any surgery
___Know patients with AV fistulas that have problems
___Not experiencing a problem with my (please specify) ______________________
___PD is my treatment choice
___Tried AV fistula but it didn’t work
___Want to wait until it is necessary
___On the transplant list – dialysis is temporary
___Afraid of blood, bleeding
___Don’t like the way fistula looks
___Other (please explain)

__________________________________________________________________________
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__________________________________________________________________________

The Renal Network, Inc. - 2009
Appendix C

Fistula Coaching Program Feedback

Facility Name: _________________________________

Facility Address: _________________________________

Facility Phone Number: _________________________________

Person completing this form: _________________________________

Scale: 1= Very helpful   2 = Somewhat helpful   3= Not helpful

1. The Coordinator Guidebook is a useful tool.  1  2  3

2. The Patient Coach Handbook is a useful tool.  1  2  3

3. Patients are interested in being patient coaches.  1  2  3

4. The most helpful part of the program is _________________________________

5. The least helpful part of the program is _________________________________

6. Since receiving this material, I have started a Fistula Coaching Program. Yes No

7. Since receiving this material, I plan to start a Fistula Coaching Program: (circle one)
   a. In the next 3 months;
   b. In the next 6 months;
   c. In the next 9 months;
   d. Unsure

8. I do not plan to start a Fistula Coaching Program because: (circle one or more)
   a. We already have a high number of patients with a fistula;
   b. No patients are interested in being coaches;
   c. No patients want another patient to talk to them;
   d. No time to start the program and supervise volunteers;
   e. Material does not provide enough information;
   f. Other (Please explain) _________________________________

Appendix D

**Fistula Coaching Program Materials Order Form**

Please complete and return order form to Patient Services Department, The Renal Network, Inc., 911 E. 86th Street, Suite 202, Indianapolis, Indiana 46240 or FAX to 317.257.8291.

**CD-ROM**
The CD includes all Fistula Coaching Program manuals and resources except the DVD which must be ordered separately.

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**PRINTED COPIES**
Order all or selected program manuals and resources. Limit 10 copies per order.

- The Fistula Coaching Program *Coordinator Guidebook* # of copies _____
- The Fistula Coaching Program *Patient Coach Handbook* # of copies _____
- *Access Care: Your Lifeline* # of copies _____
- *Arterial Venous Fistula (AVF)* # of copies _____
- *Choosing Your Vascular Access* # of copies _____
- *Ease the Ouch: Taking the fear out of AV Fistula Placement* # of copies _____
- *Fistula First Patient Resources* # of copies _____
- *Renal Outreach*
  - Frequently Asked Questions – AVF # of copies _____
  - How Do I Look # of copies _____
  - Naked Arm # of copies _____
  - One-site-It is # of copies _____

**Vascular Access DVD**

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Appendix E

**Patient Coach Handbook**

Provides tips and resources for the patient volunteer and can act as a workbook for the Coordinator to use in the training program.