A Guide for People with Parkinson's Disease

To ease the burden
To find the cure

Be Independent!

The American Parkinson Disease Association, Inc.
BE INDEPENDENT!

A SELF HELP GUIDE FOR PEOPLE WITH PARKINSON’S DISEASE

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BE INDEPENDENT
is a revision and update
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INTRODUCTION

Activities of daily living include tasks such as bathing, grooming, dressing, preparing food, eating and caring for the home. Walking and general mobility - getting from place to place - are also important aspects of a person’s life.

People with Parkinson’s disease often have tremors, rigidity and slowness of movement, all of which may interfere with their ability to care for themselves.

This booklet contains suggested techniques and useful aids which can help people to remain independent.

The adaptive devices mentioned can be purchased at a surgical supply store or through the catalogues listed in the reference section.

There are many things that you can do to increase your independence and safety in self-care and mobility.

For further information, consult your physician, occupational therapist or physical therapist.
THE BEDROOM

Your bedroom should be kept free of clutter and be large enough to allow free access to the bed, bureau, closet and hallway doors. Scatter rugs increase the risk of falling and should be avoided. If they are used, they must be taped or tacked to the floor even if they have non-skid rubber pads beneath them. Casters should be removed from furniture, since objects that roll provide unstable hand holds. Shoes and other small objects should be kept off the floor, especially at night.

Special equipment and aids can be used in your bedroom to help you maintain your independence and safety while increasing your comfort.
1. Bed pulls can be attached to the frame at the end of the bed. They are useful in assisting you in rising to a seated position or turning in bed, and can be either purchased or made at home. To make: Braid three pieces of tightly woven fabric, such as sheeting, together in a length that reaches from the base of the bed to your hand when you are lying down. Sew a large wooden curtain ring to the end to serve as a grasp. Then sew a small binder clip near the ring so that the bed pull can be clamped to the bedding and remain within your reach. Bed pulls can also be attached to the sides of the bed to assist you when turning.

2. A trapeze installed over the head of the bed can help you to change your position. It may be purchased at a surgical supply store and can be mounted to most standard beds.

3. A sturdy cardboard box can be placed under the covers at the foot of the bed. This ‘bed cradle’ keeps your feet and lower legs free of the sheets while turning.

4. A urinal may be kept within reach on a bed table, or a commode may be placed at the bedside for night time use. The urinal or commode helps reduce walks to the bathroom.

5. Disposable incontinence garments are designed to address the problem of accidental urination and may be especially helpful at night.
6. A chair with armrests and a firm seat should be part of the bedroom furniture. Dressing can be accomplished while sitting in the chair, thus eliminating the risk of falling. Try to avoid sitting in a low chair. A firm pillow, secured to the chair, makes it easier to rise from a low surface.

7. The bed should be no lower than knee height for ease in getting in and out. If your bed is too high, a carpenter can cut two or three inches off the legs. If your bed is too low, use a thicker mattress or mattress padding.

8. A railing can be installed on a bedroom wall ten inches higher than the level of the bed, and the bed placed against the wall under the railing. The railing becomes an assist for rising from and turning in bed. Commercially made bedrails are available and can be mounted on most beds. Satin sheets are smooth and can also facilitate turning.

9. If you have difficulty sitting up in bed, place a foam wedge cushion under the mattress at the head of the bed, or place wooden risers under the legs at the head of the bed.

10. Night lights should be installed in a wall socket near the bedroom door, in the hallway leading to the bathroom, and in the bathroom. They are indispensable in helping you avoid accidents.

11. A communication device such as a bell or intercom system may be needed to ensure safety at night, especially if you have decreased voice volume.
THE BATHROOM

Safety is essential in the bathroom. It is the most dangerous room in your house. The tile floor is slippery and the surfaces of the shower or tub are extremely slick, especially when wet. The average bathroom is often small and furnished with porcelain fixtures that jut out from the walls and restrict walking space. A call for help may go unheard, especially if the water is running or the door is closed.

It is important that the bathroom be made as safe as possible. Adequate equipment and awareness of danger increases the ease and safety of bathing and grooming. Bathing is easier if you are organized and keep everything that you need arranged safely within or near the tub.

BATHROOM SAFETY

1. Non-skid decals or strips, attached to a tub or shower floor, or the use of a rubber mat, helps to eliminate falls. Small bathroom rugs are easy to trip over, and should not be used. Use a large rug that covers most of the floor, wall-to-wall carpeting or bare flooring. Do not wax the floor.
BATHROOM SAFETY
(Continued)

2. Grab bars or tub rails placed in strategic locations provide balance and support for getting in and out of the tub or shower. Never use towel racks or wall soap holders as grab bars. They are not designed for this and may break away under pressure.

3. Tub seats or shower chairs make bathing easier and safer. A flexible shower hose or a hand-held shower massage allows for safer bathing while seated. A shower nozzle with a turn-off knob is more convenient than a free-flow nozzle.

4. A raised toilet seat makes sitting on and rising from the toilet easier. Arm rails attached to the toilet, or a grab bar installed on the wall adjacent to the toilet, provide convenient hand holds.

5. If you have difficulty holding objects, do not use glass tumblers. Paper or plastic cups are safer.

6. A night light should always be installed in a bathroom wall socket.

7. The hot water heater in your house should be turned down to prevent accidental scalding.
GROOMING

1. Soap on a rope keeps soap conveniently within reach while showering or taking a tub bath.

2. A suction nail brush makes grooming easier and safer. It can be secured to the tub, reducing the risk of injury from falling.

3. A long-handled sponge reaches the lower legs, feet and back. It helps eliminate bending and is necessary if you have a problem with balance. A curved bath sponge can be useful for washing your back.

4. Wash mitts are terry cloth gloves that eliminate the need for holding onto a washcloth.

5. An electric razor should be used for safety, particularly if you have hand tremor. A variety of electric razor holders, which make grasp easier, are commercially available.

6. Round-headed faucets require a twisting motion to operate. This is difficult for people with impaired strength or coordination. They can be placed with a lever-type handle or a single arm control faucet. The round-headed faucet can be improved by adding tap-turner adaptations.

7. Adding a commercially made built-up handle, a bicycle handle or a wrist cuff makes your toothbrush, hairbrush or comb handles larger and easier to grip. Extension handles may be helpful if your shoulder or arm movement is limited.
BATHROOM IDEAS

Illustrations clarify equipment discussed in the
xt; it is not necessarily used in this combination.
DRESSING

The fine hand coordination and strength needed for dressing is sometimes impaired in people with Parkinson’s disease. Pain and stiffness in your limbs can also complicate putting on and taking off your clothing, particularly underwear, socks and slacks. There are many simple and useful aids that can help you remain independent.

Try to choose clothing that is easy to manage. Loose fitting, stretchy clothes with simple fastenings are easier to put on and take off. For some people, pullover tops may be more convenient. They eliminate the need for buttoning. Front-closing garments are easier to manage than zipper and button-back garments.

Knee-length stockings can be worn instead of panty hose only if they have wide elasticized tops to prevent constriction of circulation. NEVER wear stockings rolled down and secured with a rubber band or garter. This impairs circulation.

Clothing should be placed, in order of wear, on a chair near you. Take your time and, if possible, do not allow anyone to rush you. Try to maintain your independence.

DRESSING DEVICES

1. Velcro closures are excellent substitutions for buttons and zippers. Sew tabs of velcro over the button hole and on the underside of the button. Press the velcro strips together to fasten your shirt.
DRESSING DEVICES
(Continued)

2. A button hook or button aid slips through the button hole and pulls the button back through it. The handles of these tools are more easily grasped than a small button when fine hand coordination is impaired.

3. Large, easily grasped zipper pulls or rings make opening and closing trouser flys, jackets and coats less difficult.

4. Small cuff buttons can be difficult to manipulate. Use elastic thread to sew buttons onto cuffs. Keep them buttoned all the time and slide your hands through. You can also join the cuff with a velcro closure.

5. A dressing stick or reacher is useful for pulling pants and undergarments up over your legs. It allows you to remain seated while dressing and reduces the risk of falling. Reachers are also useful for picking up objects that have dropped to the floor.

6. Elastic shoe laces need to be tied only once, thus converting laced shoes to slip-on shoes. Standard tie shoes can be closed with Velcro strips. A shoe maker can stitch them on.

7. A front-closing bra is easier to put on and take off. You can adapt a back-closing bra by sewing up the rear closure, cutting the front open and attaching velcro strips.

8. A long-handled shoehorn and a sock donner reduce bending and straining when putting on socks and shoes.
DRESSING IDEAS

BUTTON HOOK

ZIPPER PULL

ZIPPER RING
THE KITCHEN

Decreased strength, range of motion and coordination problems can limit your ability to perform kitchen activities such as: meal preparation, food storage, eating, cleaning and clearing up after meals. Many ingenious aids have been devised to improve safety and efficiency in the kitchen.

Your kitchen should be kept well organized with dishes, utensils and foods stored near to where they are used and within easy reach. Coffee and tea for instance, should be stored as close as possible to the tea kettle. Store utensils you rarely use behind those you use everyday. If you have wall space, install a pegboard at an accessible height and hang utensils there.

Pace yourself during kitchen activities and plan before you start to avoid unnecessary energy-consuming steps. If you have impaired balance, slowness of movement or decreased hand coordination, meal preparation is safer and easier if done while seated.

KITCHEN EQUIPMENT

1. A Lazy Susan, placed in the center of the kitchen table or on a counter, holds numerous frequently used items and eliminates the need to gather each one before meals. The Lazy Susan can also be used as a shelf organizer to reduce the need to reach for objects at the back of the shelf.

2. Reachers can be used in the kitchen to pick up light objects that fall to the floor. Heavy objects should be placed in counter-height cabinets.
3. A rubber pad or wet disclolth can be placed under bowls and pans to stabilize them while you are preparing food.

4. Electric can openers are useful and convenient, especially if fine hand coordination is impaired.

5. A jar opener eases the problem of opening jars.

6. A cutting board with a raised edge prevents diced vegetables and small pieces of meat from scattering off the board. A nail hammered into the board skewers food while dicing or cutting. The nail also helps when buttering bread or toast. Suction cups can be attached to the bottom of your cutting board to prevent it from sliding.

7. A microwave, used instead of a stove, reduces the risk of injury from burns.

8. A long-handled dust pan enables you to collect floor sweepings without bending to the floor. A sponge mop should be kept easily accessible as spills should be wiped up immediately to reduce the chance of falling.

9. Your strength and hand function should affect your choice of pots and pans. If you have limited strength, use aluminum pots and pans and lightweight dishes. Make sure that the shape and size of the handles are suited to your grasp strength. A long pot handle allows for two-handed lifting.

10. A pot stabilizer keeps the handle steady when you stir.

11. A kitchen scissor can help you to open plastic packages and boxes that are difficult to rip.
KITCHEN IDEAS

- Cutting Board with Lip and Suction
- Zim Jar Opener
- Pot Stabilizer
MEALTIME

There are many attractive and durable commercially available mealtime aids. They have been designed to enable you to continue to eat with as much independence as possible.

If you use a special or adapted piece of silverware at home, take it with you when you dine in a restaurant. If you have difficulty cutting food, ask the waiter to have the food cut in the kitchen before it is presented to you. This prevents someone from having to reach across the table to assist you and thus call attention to your disability. Take your time while eating and try not to let anyone rush you.
MEALTIME EQUIPMENT

1. Attachable plate guards provide a rim on one side of the plate. Food, especially small vegetables, can be pushed against the guard, where they fall onto the fork. Plate guards also prevent spills. Scoop dishes contoured with raised edges serve the same purpose.

2. Silverware with built up plastic handles are more easily grasped. Tubular foam padding can be attached to the utensil to widen the grip.

Soup spoons can be used instead of forks when eating small pieces of food. Sporks are a combination spoon and fork. The one utensil can spear as well as hold food. A rocking knife may be used instead of a straight if you have problems with coordination. Weighted utensils may help to decrease hand tremors, thus allowing the utensil to reach your mouth more easily.

3. If you have a tremor, flexible plastic straws help you to drink.

4. A mug with a large handle for easy grasp should be used if your tremor is severe. An insulated mug with a lid reduces the risk of burns from spills when drinking hot liquids.

5. A rubber pad or a moist paper towel can be placed under plates, cups and serving dishes to keep them from sliding.
MEALTIME IDEAS

THERMAL MUG

PLATE WITH FOOD GUARD

BUILT UP HANDLE (tubular foam padding)

ROCKER KNIFE
WALKING

The ability to get from one place to another inside or outside the home is very important. There are a number of assistive devices which can help a person with decreased balance, coordination, or mobility to walk safely.

Canes can be used to compensate for minor balance problems. They come in a variety of shapes and sizes and increase your base of support.

The standard J-Handle cane offers some stability as well as a sense of security. An ortho-cane or a quad-cane may also be used. Each offers an increasing degree of support and balance.

If more assistance than a cane is needed, a walker can be prescribed. A walker which folds is good if you need to store or transport it in limited space - for example, in a car. Wheels can be added if you have difficulty coordinating the advancement of the walker or are usable to lift it off the floor. A braking mechanism which locks with downward pressure can be attached to the front or back wheels. It is important to note, however, that although the rolling walker is easier to advance, it can be unsafe on rugs and other uneven surfaces.

If you are unable to walk, or can walk only short distances in your home, a wheelchair provides more functional mobility.

In order to best suit your individual needs, a physical therapist should be consulted so that the appropriate ambulatory device or wheelchair is provided.
WALKING IDEAS

Standard J-Handle (Straight Cane)

Ortho Cane

Quad Cane

Walker
NEGOTIATING STAIRS

Stairs often become a major barrier to a person who has limited strength, balance, and mobility. The following guidelines make stair climbing easier.

If there is a handrail available, use it as long as it is well secured. Hold onto the hand railing with one hand and an assistive device, if needed, in the other hand. Both hands can also be placed on the handrail to sidestep up and down the stairs one at a time.

If you are unable to go up or down the stairs safely in a step-over-step manner, negotiate the stairs one step at a time. Place one foot on the step; place the second foot on the same step before you move on to the next.

If someone is assisting you, that person should stay by your side. The assisting person should stagger their feet so that their lead foot is one step down from yours. This maintains good balance.

If you cannot safely climb stairs, you can be carried up and down in a wheelchair. A lift may be installed, but it is expensive.

Specific instructions for walking up and down the stairs or being assisted in a wheelchair can best be given by a physical therapist.
GETTING IN OR OUT OF A CAR

There are ways to make getting in or out of a car easier. First, the car must be parked far enough away from the curb so that you can step onto the level ground before you go into or get out of the car. To get into a car, turn so that you back in for the last steps. Your buttocks should lead. Then sit down and swing your legs in.

To exit the car, swing both legs out together and stand up. Sit in the front or back seat, whichever gives you more room. Use pillows to make it easier to get up from a low car. Specific techniques should be taught by and practiced with a physical therapist or occupational therapist.
GETTING INTO A CAR

1. Stand on the left side of the car.
2. Open the car door and step into the car.

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MISCELLANEOUS TIPS

If you have a problem with shuffling, small steps and stopping while walking, arrange the furniture so as to avoid congested areas. Keep hallways free of obstacles. Plan a route through the house so that there is always a safe handhold available in case you lose your balance.

Railings can be installed on the walls to provide support. Your family should consult with you before they rearrange the furniture so that you do not lose familiarity with your surroundings.

Avoid low couches and chairs as it is often extremely difficult to rise from them without help. A straight back chair with armrests and a firm seat is easier to get up from. A firm cushion can be used to acquire the height that is suitable for you. Pneumatic lifter seats can assist someone who has severe difficulty rising from a chair.

Handrails should be installed on all staircases, especially those outside.

Use a carpet sweeper instead of a vacuum. It is lighter and easier to manipulate.

The “Fone Holder” is a long, flexible shaft that attaches to most tables and can be positioned to hold the telephone receiver so a person can use the hand set without having to move or even touch it. Another device adapts huge push buttons to the small touch-tone buttons of a standard phone to make dialing easier.
Handwriting can be a serious problem for persons with Parkinson’s disease. Various pens, pencils and writing devices are available to stabilize your grip. A weighted pen may help reduce tremors and improve writing.

A door knob turner fits over the door handle and converts the round knob into a lever. This makes it easier to open.
A WORD TO THE FAMILY

In order to preserve independence in activities of daily living, people with Parkinson’s disease should do all that they can for themselves. Because of tremor, rigidity and slowness of movement, each activity may take more time than it used to.

It is tempting to do or to complete tasks for people. It saves time and, perhaps, frustration. However, this may lead to dependence, because it decreases people’s motivation to help themselves.

The physical ability of persons with Parkinson’s disease varies throughout the day in response to anti-Parkinson’s medication. Tremor, rigidity and slowness of movement may be more pronounced in the morning than in the afternoon. People’s ability to dress or to eat may be impaired at one time and not another.

To decrease misunderstanding and further frustration, families should be aware that their relatives are not malingering but that it is the variability of the disease that causes fluctuation in independence. People may require help some of the time, but not all of the time.

It is vitally important for the families of people with Parkinson’s disease to help them remain as independent as possible.
Resources for Independent Living

Listed are some companies that feature products, equipment and clothing designed to make self-care skills easier. You may want to call or write:

Adaptability
P.O. Box 515
Colchester, CT 06415
800-243-9232

After Therapy Catalog
North Coast Medical
187 Stauffer Boulevard
San Jose, CA 95125-1042
800-821-9319

American Walker
742 Market Street
Oregon, WI 53575
608-835-9255

Bell Atlantic Center for Customers with Disabilities
280 Locke Drive, 4th Floor
Marlboro, MA 01752
800-974-6006

Bruce Medical Supply
411 Waverly Oaks Rd.
P.O. Box 9166
Waltham, MA 02254
800-225-8446
Resources for Independent Living
(Continued)

Comfort House
189 Frelinghuysen Avenue
Newark, NJ 07114-1595
800-359-7701
www.comforthouse.com

Disabled Doesn’t Mean Inable
Adaptive Aids for Transportation
Becky Plank
909 E. Skagway Avenue
Tampa, FL 33604-1747
813-932-7367

Dr. Leonard’s Health Care Catalog
74 20th Street
Brooklyn, NY 11232
800-785-0880

Dressing Tips and Clothing Res. for
Making Life Easier
The Best 25 Catalogues Resources for
Making Life Easier
Shelley Peterman Schwarz
933 Chapel Hill Road
Madison, WI 53711
www.makinglifeeasier.com
help@makinglifeeasier.com
Resources for Independent Living
(Continued)

Durable Medical Equipment
12985 Waine Road
Livonia, MI 48150
800-877-7285

Durable Medical Equipment (over 3500)
Plate Guards, Aids for Daily Living
Yes I Can
35-325 Date Palm Drive, Suite 131
Cathedral City, CA 92234
800-366-4226
760-321-1717

Enrichments or Preston
P.O. Box 5050
Bolingbrook, IL 60440-5050
800-323-5547

Fashion Ease
1541 60th Street
Brooklyn, NY 11219
800-221-8829
718-871-8188 (NY State)
Fax: 718-436-2067

Independent Living Aids Inc.
27 East Mall
Plainview, NY 11803
800-537-2118
Resources for Independent Living (Continued)

J.C. Penny’s Easy Dressing Catalog
P.O. Box 2021
Milwaukee, WI 53201
800-222-6161

Patients Transfer Systems
Beatrice M. Brantman, Inc.
207 E. Westminster
Lake Forest, IL 60045
800-232-7987

Personal Pager
The Greatest of Ease Company
2443 Fillmore Street, #345
San Francisco, CA 94115
415-441-6649

Rand Voice Amplifier
Park Surgical Company, Inc.
5001 New Utrecht Avenue
Brooklyn, NY 11219
718-436-9200
800-633-7878

Sears Health Care Catalog
Sears Roebuck and Company
P.O. Box 804203
Chicago, IL 60680-4203
800-326-1750
Resources for Independent Living (Continued)

The Speedo Aquatic Exercise System
7911 Haskell Avenue
Van Nuys, CA 91409
800-547-8770

The Do Able Renewable Home
Consumer Affairs Program Dept.
American Association of Retired Persons
(AARP)
800-424-3410

Voice Amplifier
Luminaud Inc.
8688 Tyler Blvd.
Mentor, OH 44060-4348
800-255-3408

Voice Amplifier
Anchor Audio, Inc.
3415 Lomita Blvd.
Torrance, CA 90505
800-262-4671
310-784-2300

Voice Amplifiers
Phillips Consumers Communications
800-233-1222

Walkers
Noble Motion Inc.
P.O. Box 5366
5871 Centre Avenue
Pittsburgh, PA 1520-0366
800-234-9255
APDA Information and Referral Centers

Alabama, Birmingham
University of Alabama at
Birmingham
205-934-9100

Arizona, Tucson
University of Arizona
520-326-5400

Arkansas, Hot Springs
St. Joseph's Regional
Health Center
800-407-9295
501-518-1690

California, Los Angeles
Cedars-Sinai Health System
310-855-7933

California, San Diego
520-326-5400

California, San Francisco
Seton Medical Center
650-991-6391

Connecticut, New Haven
Hospital of Saint Raphael
203-789-3936

Florida, Jacksonville
Mayo Clinic, Jacksonville
904-953-7030

Florida, Pompano Beach
North Broward Medical Center
800-278-5386

Florida, St. Petersburg
Columbia Edward White Hospital
813-862-3560

Georgia, Atlanta
Emory University School of
Medicine
404-778-5120

Idaho, Boise
St. Alphonsus Medical Center
208-367-6570

Illinois, Chicago
Glenbrook Hospital
847-657-5787

* The Arlette Johnson
Young Parkinson Information
& Referral Center
Glenbrook Hospital
847-657-5787
800-223-9776 - (Out of IL)

Louisiana, New Orleans
School of Medicine, LSU
504-566-6554

Maryland, Baltimore
Johns Hopkins Outpatient Center
410-955-8795

Massachusetts, Boston
Boston University School of
Medicine
617-638-8466

Minnesota, Minneapolis
Abbott Northwestern Hospital
Minneapolis Neurosciences Inst.
612-863-5580

Missouri, St. Louis
Washington University
Medical Center
314-362-3299

Montana, Great Falls
Benefit Health Care
800-233-9040
406-455-2964

Nebraska, Omaha
Information & Referral Center
402-551-9311

Nevada, Las Vegas
Medical Associates
UNLV School of Medicine
702-671-2356

** Nevada, Reno
V.A. Hospital
702-328-1715

New Jersey, New Brunswick
Robert Wood Johnson
University Hospital
732-745-7520

New Mexico, Albuquerque
HEALTHSOUTH
Rehabilitation Hospital
800-278-5386

New York, Albany
The Albany Medical College
518-452-2749

New York, Far Rockaway
Peninsula Hospital
718-945-7079

New York, Manhattan
New York University
212-993-1379

New York, Old Westbury
New York College of
Osteopathic Medicine
516-626-6114

New York, Smithtown
St. John's Episcopal Hospital
516-862-3560

New York, Staten Island
Staten Island University Hospital
718-226-6129

North Carolina, Durham
Duke University Medical Center
919-681-2033

Ohio, Cincinnati
University of Cincinnati
Medical Center
513-558-6770
800-840-2732

Oklahoma, Tulsa
Hillcrest Medical Center
918-747-3747
800-364-4450

Pennsylvania, Philadelphia
Crozer-Chester Medical Center
610-447-2911

Pennsylvania, Pittsburgh
Allegheny General Hospital
412-441-4100

Rhode Island, Pawtucket
Memorial Hospital of RI
401-729-3165

Tennessee, Memphis
Methodist Hospital
901-726-8141

Tennessee, Nashville
Centennial Medical Center
615-342-4635
800-493-2842

Texas, Bryan
St. Joseph Regional
Rehabilitation Center
409-821-7523

Texas, Dallas
Presbyterian Hospital of Dallas
214-345-4224
800-725-2732

Texas, Lubbock
Methodist Hospital
806-785-2732
800-687-5489

Texas, San Antonio
The University of Texas HSC
210-567-6698

Utah, Salt Lake City
University of Utah, School of
Medicine
801-585-2354

Vermont, Burlington
University of Vermont
Medical Center
804-982-4482

Virginia, Charlottesville
University of Virginia
Medical Center
804-982-4482

Washington, Seattle
University of Washington
206-543-5567

Wisconsin, Appleton
Appleton Medical Center
920-831-1844
888-797-2732

Dedicated Centers

*Young Parkinson

**Armed Forces Veterans
THE AMERICAN PARKINSON DISEASE ASSOCIATION, INC.
1250 HYLAN BLVD., SUITE 4B
STATEN ISLAND, NY 10305
800-223-2732 (TOLL FREE NUMBER)

APDA West Coast Office
Avco Center Building
10850 Wilshire Boulevard
Los Angeles, CA 90024
800-908-2732

APDA Washington D.C. Office
975 Powhaton Street
Alexandria, VA 22314
800-684-2732