

# RESOURCE GUIDE & INFORMATION



**Huntington's Disease  
Society of America**

 **MASSACHUSETTS & RHODE ISLAND CHAPTER**



## Community Action Agencies

PAGE 03

---



## Legal Assistance

PAGE 21

---



## Social Security Disability

PAGE 21

---



## Mental Health Resources

PAGE 08

---



## Long Term Care

PAGE 25

---



## HD Resources

PAGE 12

---



## Advocacy / Research

PAGE 26

---



## HD Testing

PAGE 16

---



## Local Support Groups

PAGE 28

---



## Reproductive Help

PAGE 19

---



## Brain Donation

PAGE 29

---



## HD-Specific Providers

PAGE 20

---



## Comprehensive Care Assistance Programs

PAGE 30

# MASSACHUSETTS COMMUNITY ACTION AGENCIES

Provides assistance with GED and ESL education, job training, head start and day care, low-income home energy assistance programs, weatherization assistance programs, homeless prevention programs, senior services, temporary emergency food assistance programs, and housing support programs. Available services vary from agency to agency.

Please reference the list below to find your Community Action Agency. You can also search for your local Community Action Agency here: <https://www.masscap.org/agencies/>

## Action for Boston Community Development, Inc. (ABCD)

178 Tremont St.

Boston, MA 02111

Phone: 617-357-6000 Fax: 617-482-4859

[www.bostonabcd.org](http://www.bostonabcd.org)

Cities/Towns in the Service Area: Boston, Brookline, Everett, Malden, Medford, Melrose, Newton, Stoneham, Winchester, Woburn

## Action, Inc. (Action)

180 Main St.

Gloucester, MA 01930

Phone: 978-282-1000 Fax: 978-283-0523

[www.actioninc.org](http://www.actioninc.org)

Cities/Towns in the Service Area: Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Wenham

## Berkshire Community Action Council, Inc. (BCAC)

1531 East Street

Pittsfield, MA 01201

Phone: 413-445-4503 Fax: 413-447-7871

[www.bcacinc.org](http://www.bcacinc.org)

Cities/Towns in the Service Area: Adams, Alford, Becket, Cheshire, Clarksburg, Dalton, Egremont, Florida, Great Barrington, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Monterey, Mount Washington, New Ashford, New Marlborough, North Adams, Otis, Peru, Pittsfield, Richmond, Sandisfield, Savoy, Sheffield, Stockbridge, Tyringham, Washington, West Stockbridge, Williamstown, and Windsor

## Cambridge Economic Opportunity Committee, Inc. (CEOC)

11 Inman St.

Cambridge, MA 02139

Phone: 617-868-2900 Fax: 617-868-2395

<https://ceoccambridge.org/>

Cities/Towns in the Service Area: Cambridge

## Citizens for Citizens, Inc. (CFC)

264 Griffin St.

Fall River, MA 02724

Phone: 508-679-0041 Fax: 508-324-7503

[www.cfcinc.org](http://www.cfcinc.org)

Cities/Towns in the Service Area: Attleboro, Berkley, Dighton, Fall River, Freetown, Lakeville, Rehoboth, Seekonk, Somerset, Swansea, Taunton, Westport

## Community Action Agency of Somerville, Inc. (CAAS)

66-70 Union Square, #104

Somerville, MA 02143

Phone: 617-623-7370 Fax: 617-628-2512

[www.caasomerville.org](http://www.caasomerville.org)

Cities/Towns in the Service Area: Somerville

## Community Action Committee of Cape Cod & Islands, Inc. (CACCI)

372 North St.

Hyannis, MA 02601

Phone: 508-771-1727 Fax: 508-775-7488

[www.cacci.cc](http://www.cacci.cc)

Cities/Towns in the Service Area: Barnstable, Bourne, Brewster, Chatham, Dennis, Edgartown, Falmouth, Gayhead, Gosnold, Harwich, Hyannis, Mashpee, Nantucket, Oak Bluffs, Provincetown, Sandwich, Tisbury, Truro, Vineyard Haven, Wareham, and Yarmouth

## Community Action, Inc. (CAI)

3 Washington Square  
Haverhill, MA 01830

Phone: 978-373-1971 Fax: 978-469-8392

[www.communityactioninc.org](http://www.communityactioninc.org)

Cities/Towns in the Service Area: Amesbury,  
Boxford, Georgetown, Groveland, Haverhill,  
Merrimac, Newbury, Newburyport, Rowley,  
Salisbury, West Newbury

## Lynn Economic Opportunity Council (LEO)

181 Union St. #209  
Lynn, MA 01901

Phone: 781-581-7220 Fax: 781-581-5320

[www.leoinc.org](http://www.leoinc.org)

Cities/Towns in the Service Area: Lynn, Lynnfield,  
Marblehead, Nahant, Saugus, Swampscott, Wakefield

## Community Action Programs Inter- City, Inc. (CAPIC)

100 Everett Ave. #14  
Chelsea, MA 02150

Phone: 617-884-6130 Fax: 617-889-8110

[www.capicinc.org](http://www.capicinc.org)

Cities/Towns in the Service Area: Chelsea,  
Melrose, Revere, Wakefield, Winthrop

## Making Opportunity Count (MOC)

601 River St.

Fitchburg, MA 01420

Phone: 978-345-7040 Fax: N/A

[www.mocinc.org](http://www.mocinc.org)

Cities/Towns in the Service Area: Ashburnham,  
Ashby, Athol, Ayer, Barre, Berlin, Bolton, Clinton,  
Fitchburg, Gardner, Groton, Hardwick, Harvard,  
Hubbardston, Lancaster, Leominster, Lunenburg,  
New Braintree, Petersham, Phillipston, Princeton,  
Royalston, Shirley, Sterling, Templeton, Townsend,  
Westminster, Winchendon

## Community Teamwork, Inc. (CTI)

155 Merrimack St.  
Lowell, MA 01852

Phone: 978-459-0551 Fax: 978-453-9128

[www.commteam.org](http://www.commteam.org)

Cities/Towns in the Service Area: Acton,  
Amesbury, Andover, Arlington, Ashby, Ayer,  
Bedford, Belmont, Beverly, Billerica, Boxford,  
Burlington, Carlisle, Chelmsford, Danvers, Dracut,  
Dunstable, Essex, Everett, Georgetown,  
Gloucester, Groton, Groveland, Hamilton,  
Haverhill, Ipswich, Lawrence, Lexington,  
Littleton, Lowell, Lynnfield, Malden, Manchester,  
Marblehead, Medford, Melrose, Merrimac,  
Methuen, Middleton, Nahant, Newbury,  
Newburyport, North Andover, North Reading,  
Peabody, Pepperell, Reading, Rockport, Rowley,  
Salem, Salisbury, Saugus, Stoneham,  
Swampscott, Tewksbury, Topsfield,  
Tyngsborough, Wakefield, Waltham, Watertown,  
Wenham, West Newbury, Westford, Wilmington

## South Middlesex Opportunity Council, Inc. (SMOC)

7 Bishop St.

Framingham, MA 01702

Phone: 508-872-4853 Fax: 508-620-2310

[www.smoc.org](http://www.smoc.org)

Cities/Towns in the Service Area: Acton, Ashland,  
Bellingham, Blackstone, Boxborough, Concord,  
Dover, Framingham, Georgetown, Grafton, Haverhill,  
Holliston, Hopedale, Hudson, Lincoln, Littleton,  
Marlborough, Maynard, Medfield, Medway, Mendon,  
Milford, Millbury, Millis, Natick, Northborough,  
Northbridge, Sherborn, Shrewsbury, Southborough,  
Stoneham, Stow, Sudbury, Upton, Uxbridge,  
Wayland, Wellesley, Weston

## Springfield Partners for Community Action, Inc. (SPCA)

721 State St. 2nd Floor

Springfield, MA 01109

Phone: 413-263-6500 Fax: 413-263-6511

[www.springfieldpartnersinc.com](http://www.springfieldpartnersinc.com)

Cities/Towns in the Service Area: Springfield

## Quincy Community Action Programs, Inc. (QCAP)

1509 Hancock St.

Quincy, MA 02169

Phone: 617-479-8181 Fax: 617-479-7228

[www.qcap.org](http://www.qcap.org)

Cities/Towns in the Service Area: Braintree, Hull, Milton, Quincy, Weymouth

## Valley Opportunity Council, Inc. (VOC)

300 High St.

Holyoke, MA 01040

Phone: 413-552-1554 Fax: 413-552-1558

[www.valleyopp.com](http://www.valleyopp.com)

Cities/Towns in the Service Area: Agawam, Ashby, Blandford, Brimfield, Chester, Chicopee, East Longmeadow, Granby, Granville, Hampden, Holland, Holyoke, Longmeadow, Ludlow, Monson, Montgomery, Palmer, Russell, South Hadley, Southwick, Springfield, Tolland, Wales, West Springfield, Westfield, Wilbraham

## South Shore Community Action Council, Inc. (SSCAC)

71 Obery St.

Plymouth, MA 02360

Phone: 508-747-7575

Fax: 508-747-1250

[www.sscac.org](http://www.sscac.org)

Cities/Towns in the Service Area: Barnstable, Bourne, Brewster, Carver, Chatham, Chilmark, Cohasset, Dennis, Duxbury, Eastham, Falmouth, Gayhead, Gosnold, Halifax, Hanover, Harwich, Hingham, Hull, Hyannis, Kingston, Marshfield, Mashpee, Middleborough, Nantucket, Norwell, Oak Bluffs, Orleans, Pembroke, Plymouth, Plympton, Provincetown, Sandwich, Scituate, Truro, Wareham, Wellfleet, West Tisbury, Yarmouth

## People Acting in Community Endeavors, Inc. (PACE)

166 William Street

New Bedford, MA 02742

Phone: 508-999-9920

Fax: 508-999-3728

<http://www.paceinfo.org>

Cities/Towns in the Service Area: Acushnet, Dartmouth, Fairhaven, Marion, Mattapoiset, New Bedford, Rochester

## Self Help, Inc. (SHI)

45 Pearl St.

Brockton, MA 02301

Phone: 508-588-0447 Fax: 508-588-1266

[www.selfhelpinc.org](http://www.selfhelpinc.org)

Cities/Towns in the Service Area: Abington, Attleboro, Avon, Bridgewater, Brockton, Canton, Dedham, Easton, Foxborough, Franklin, Hanson, Holbrook, Mansfield, Middleborough, Needham, Norfolk, North Attleboro, Norton, Norwood, Plainville, Randolph, Raynham, Rockland, Stoughton, West Bridgewater, Westwood, Whitman, Wrentham

## Worcester Community Action Council, Inc. (WCAC)

18 Chestnut St.

Worcester, MA 01608

Phone: 508-754-1176 Fax: 508-754-0203

[www.wcac.net](http://www.wcac.net)

Cities/Towns in the Service Area: Auburn, Boylston, Brimfield, Brookfield, Charlton, Clinton, Douglas, Dudley, East Brookfield, Grafton, Granville, Hardwick, Holden, Holland, Hopedale, Leicester, Mendon, Milford, Millbury, Millville, Monson, New Braintree, North Brookfield, Northborough, Northbridge, Oakham, Oxford, Palmer, Paxton, Rutland, Shrewsbury, Southbridge, Spencer, Sterling, Sturbridge, Sutton, Upton, Uxbridge, Wales, Warren, Webster, West Boylston, West Brookfield, Westborough, Worcester

## Greater Lawrence Community Action Council (GLCAC)

305 Essex St.

Lawrence, MA 01840

Phone: 978-681-4900 Fax: 978-681-4949

[www.glcac.org](http://www.glcac.org)

Cities/Towns in the Service Area: Andover, Lawrence, Methuen, and North Andover

## Community Action of Pioneer Valley

393 Main St.

Greenfield, MA 01301

Phone: 413-774-2318 Fax: 413-773-3834

Cities/Towns in the Service Area: Agawam, Amherst, Ashfield, Athol, Belchertown, Bernardston, Blandford, Buckland, Chester, Chesterfield, Colrain, Conway, Cummington, Easthampton, Erving, Gill, Goshen, Granby, Granville, Greenfield, Hadley, Heath, Huntington, Leverett, Leyden, Ludlow, Middlefield, Monroe, Montague, Montgomery, Northampton, Northfield, Orange, Petersham, Phillipston, Plainfield, Rowe, Royalston, Russell, Shelburne, South Hadley, Southampton, Southwick, Sunderland, Tolland, Ware, Wendell, West Springfield, Westfield, Westhampton, Whately, Williamsburg

## North Shore Community Action Programs, Inc. (NSCAP)

119 Rear Foster St. Building 13

Peabody, MA 01960

Phone: 978-531-0767 Fax: 978-531-1012

[www.nscap.org](http://www.nscap.org)

Cities/Towns in the Service Area: Beverly, Danvers, Marblehead, Middleton, Peabody, Salem, Topsfield

# RHODE ISLAND

Provides assistance with GED and ESL education, job training, head start and day care, low-income home energy assistance programs, weatherization assistance programs, homeless prevention programs, senior services, temporary emergency food assistance programs, and housing support programs. Available services vary from agency to agency.

Please reference the list below to find your Community Action Agency. You can also search for your local Community Action Agency here:  
<https://www.ricommunityaction.org/find-your-community-action-agency/>

## Blackstone Valley Community Action Program

32 Goff Avenue

Pawtucket, Rhode Island 02860

Phone: 401-723-4520 Fax: 401-725-6550

<https://bvcap.org/>

Cities/Towns in the Service Area: Pawtucket, Central Falls, Lincoln, Cumberland, Woonsocket

## Community Action Partnership of Providence County

518 Hartford Avenue.

Providence, RI 02909

Phone: 401-273-2000 Fax: 401-273-2007

<https://cappri.org/>

Cities/Towns in the Service Area: All of Providence County

## Community Care Alliance

800 Clinton St.

Woonsocket, RI 02895

Phone: 401-235-7000 Fax: N/A

<https://www.communitycareri.org/>

Cities/Towns in Service Area: Woonsocket

## Comprehensive Community Action Program

311 Doric Avenue

Cranston, RI 02910-2903

Phone: 401-467-9610 Fax: N/A

<https://www.comcap.org/>

Cities/Towns in the Service Area: Cranston, Foster, Scituate, Coventry

## Tri-County Community Action Agency

**Location 1:** 1126 Hartford Avenue

Johnston, RI 02919

Phone: 401-351-2750 Fax: N/A

Cities/Towns in Service Area: North Providence, Johnston, Smithfield, North Smithfield, Burrillville, Gloucester

**Location 2:** 1935 Kingstown Rd.

Wakefield, RI 02879

Phone: 401-789-3016 Fax: N/A

Cities/Towns in Service Area: Exeter, Charlestown, Narragansett, Westerly, Hopkinton, North Kingstown, South Kingstown, Richmond, West Greenwich, New Shoreham

## East Bay Community Action Program

**Location 1:** 19 Broadway

Newport, RI 02840

Phone: 401-847-7821 Fax: N/A

Cities/Towns in the Service Area: Tiverton, Little Compton, Portsmouth, Middletown, Newport, Jamestown

**Location 2:** 100 Bullocks Point Ave.

Riverside, RI 02915

Phone: 401-437-1000 Fax: N/A

Cities/Towns in the Service Area: East Providence, Barrington, Warren, Bristol

**Both Locations:** [www.ebcap.org](http://www.ebcap.org)

## Westbay Community Action, Inc.

487 Jefferson Blvd

Warwick, RI 02886

Phone: 401-732-4666 Fax: N/A

<https://westbaycap.org/>

Cities/Towns in the Service Area: Warwick, West Warwick, East Greenwich

# MENTAL HEALTH & SUBSTANCE ABUSE RESOURCES



## MASSACHUSETTS AND RHODE ISLAND

---

**1**

### **SAMHSA NATIONAL HELPLINE**

SAMHSA's National Helpline, [1-800-662-HELP \(4357\)](tel:1-800-662-HELP(4357)), (also known as the Treatment Referral Routing Service) or TTY: [1-800-487-4889](tel:1-800-487-4889) is a confidential, free, 24-hour-a-day, 365-day-a-year, information service, in English and Spanish, for individuals and family members facing mental and/or substance use disorders. This service provides referrals to local treatment facilities, support groups, and community-based organizations. Callers can also order free publications and other information. You can also search for treatment services here: <https://findtreatment.gov/>

**2**

### **HDSA TELEHEALTH THROUGH AMWELL**

HDSA's FREE Telehealth Program, powered by Amwell, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA's free telehealth portal, visit [www.hdsa.amwell.com](http://www.hdsa.amwell.com) or download the free Amwell® app and use the Service Key: HDSA to access the Huntington's disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in their state. The sessions are free for families affected by HD, and no insurance is required. You can have up to 8 sessions per year.

**3**

### **HDSA SUPPORT GROUPS**

Regional, Virtual and In Person:  
<https://massri.hdsa.org/about/new-england-region-support-groups>  
National, Virtual: <https://hdsa.org/find-help/community-social-support/hdsa-support-groups/>



# MASSACHUSETTS-ONLY RESOURCES

---

1

## **MASSACHUSETTS BEHAVIORAL HEALTH HELP LINE (BHHL)**

Can connect you directly to clinical help, when and where you need it. Available 24 hours per day, 7 days per week, 365 days per year (including holidays). It's free, confidential, and no health insurance is required. Real-time interpretation in 200+ languages. Deaf or hard of hearing? Contact MassRelay at 711

- Call or text 833-773-2445
- Live chat available at: <https://www.masshelpline.com/>
- Search the behavioral health resource directory at: <https://www.masshelpline.com/MABHHLTreatmentConnectionResourceDirectory>

2

## **MOBILE CRISIS/EMERGENCY INTERVENTION**

If you or a family member are experiencing a mental health or substance use disorder crisis and feel like you need help within one hour, you can call 1-877-382-1609. Provides crisis assessment, intervention, and stabilization services. Instead of going to the emergency room, you can get these services in your home or at other locations in the community. MCI (Mobile Crisis Intervention) services are available to people of all ages who are covered by MassHealth or Medicare. You can also get these services if you are uninsured. If you have a different health plan, you still may be able to get MCI services.

3

## **NAMI COMPASS**

COMPASS is the information and referral helpline at NAMI Massachusetts. They provide resources and support to help people navigate the complex mental health system and problem solve in difficult circumstances. Trained Navigators are available to answer a wide range of questions and refer to community resources. The COMPASS helpline is available Monday through Friday, 9 am – 5 pm. Call the helpline at 617-704-6264 or 1-800-370-9085, or email them at [compass@namimass.org](mailto:compass@namimass.org).

4

## **MASSACHUSETTS SUBSTANCE USE HELPLINE**

The Helpline is the only statewide, public resource for finding substance use treatment and recovery services. Helpline services are free and confidential. Caring, trained Specialists will help you understand the treatment system and your options. Call the helpline for live help at [1-800-327-5050](tel:1-800-327-5050) or search the directory online at: <https://helplinema.org/>

# 5

## THERAPY MATCHER REFERRAL SERVICE

Free telephone referral service that connects people with licensed independent clinical social workers (LICSWs) across Massachusetts.

- [www.TherapyMatcher.org](http://www.TherapyMatcher.org)
- (617) 720-2828 or (800) 242-9794
- [info@therapymatcher.org](mailto:info@therapymatcher.org)

# RHODE ISLAND-ONLY RESOURCES

---

## 1

### **BH LINK**

If you are struggling with alcohol or drug use, help is waiting across Rhode Island. All you have to do is reach out. There are many treatment and recovery options to help you with a plan that will work for you. Call 988 to learn more and connect with a BH Link trained crisis counselor. For walk-in behavioral health services, the BH Link Walk-In/Drop Off Triage Center is open 24/7 to connect people to immediate, stabilizing emergency behavioral health services and long-term care and recovery supports. BH Link is located at 975 Waterman Ave., East Providence, RI. People with moderate to severe opioid use disorder (OUD) can access telehealth service for initiation of buprenorphine treatment 24 hours a day, seven days a week. Call Rhode Island's Buprenorphine Hotline 401-606-5456.

---

## 2

### **UNITED WAY OF RHODE ISLAND AND CVS HEALTH FOUNDATION**

Working together to help those impacted by the opioid crisis. Our goal is to connect Rhode Islanders with treatment resources, increase addiction awareness, and find options that work:

- 2-1-1 staff received specialized training in answering addiction-related calls.
- We've added three-way calling with Anchor Recovery, a comprehensive substance abuse treatment organization, to assist in urgent situations.
- The 2-1-1 Outreach RV travels to locations throughout the state, including monthly visits to CVS stores, raising awareness and bringing addiction recovery services directly into communities.

---

## 3

### **ANCHOR RECOVERY**

As an Anchor Recovery Community Center member, you will have access to our recovery community centers, located in Providence and Warwick, RI. We provide a safe, welcoming environment for all individuals in recovery from substance use disorders. (401) 889-5770

---

## 4

### **MENTAL HEALTH ASSOCIATION OF RHODE ISLAND**

Our mission is to promote and nourish mental health through advocacy, education, and policy development. The Mental Health Association of Rhode Island is the watchdog of the mental health community. We increase consumers' access to treatment and services, and improve the lives of people touched by mental illness. Our work includes: Policy and Advocacy, Research, Awareness and Education, and Diversity, Equity, and Inclusion. You can review the MHARI resource guide here:

<https://mhari.org/resources/>

# HUNTINGTON'S DISEASE SPECIFIC RESOURCE WEBSITES

There are several valuable resources available for individuals and families affected by Huntington's disease. These resources can provide information, support, and assistance in managing the challenges of the condition. Here are some of the key Huntington's disease resources:



## Huntington's Disease Society of America (HDSA)

<https://hdsa.org/>

HDSA is a national non-profit organization that provides support, advocacy, and resources for individuals and families affected by HD. They offer information about the disease, support groups, educational materials, and opportunities to get involved in research and fundraising efforts.



## Huntington's Disease Youth Organization (HDYO)

<https://en.hdyo.org/>

HDYO focuses on supporting young individuals impacted by Huntington's disease. They offer resources, education, and events specifically tailored to young people who have a family history of the condition.



## Huntington's Disease Clinical Trials Database

<https://clinicaltrials.gov/>

This database provides information on ongoing and completed clinical trials related to Huntington's disease. It allows individuals to search for clinical trials and potentially participate in research studies.



## Huntington's Disease Outreach Project for Education at Stanford

[https://web.stanford.edu/group/hopes/cgi-bin/hopes\\_test/](https://web.stanford.edu/group/hopes/cgi-bin/hopes_test/) HOPES is a resource providing comprehensive information about Huntington's disease, including research updates, treatment options, and scientific breakthroughs.



## National Institute of Neurological Disorders and Stroke (NINDS)

<https://hdsa.org/>

HDSA is a national non-profit organization that provides support, advocacy, and resources for individuals and families affected by HD. They offer information about the disease, support groups, educational materials, and opportunities to get involved in research and fundraising efforts.



## Help 4 HD

<https://www.help4hd.org/> Help 4 HD's mission is to educate the world about Huntington's disease (HD) and Juvenile Huntington's disease (JHD) through its multimedia communications platform. Through live events, Help 4 HD Radio, Help 4 JHD Radio, symposia, conferences, publications, and support groups, Help 4 HD brings education, information, and resources to the global community, partnering with medical professionals, researchers, institutions and industry for the most current and credible information and resources available.



## HDSA Telehealth

HDSA's FREE Telehealth Program, makes it easy for you to talk to mental health therapists from the comfort of your home. To utilize HDSA's free telehealth portal, visit [www.hdsa.amwell.com](http://www.hdsa.amwell.com) or download the free Amwell® app and use the Service Key: HDSA to access the Huntington's disease practice. On the site, patients can schedule appointments with social workers and psychologists licensed in their state. The sessions are free for families affected by HD, and no insurance is required.

## HDSA Support Groups- Massachusetts

<https://massri.hdsa.org/about/new-england-region-support-groups>





## HD Reach

<https://www.hdreach.org/> HD Reach is working to improve the care and quality of life for those affected by Huntington's disease. Founded as a nonprofit in 2009, we provide connections to medical providers, referrals to local services, care management, family support, education, and anonymous genetic testing.



## Champions for HD

<https://www.championsforhd.org/>

Champions for HD is a non-profit in the fight against Huntington's Disease. Founded in 2018 by Shelby Lentz, who drew inspiration from the Rocky Balboa movies, this non-profit aims to not only fight for a cure for Huntington's Disease, and Juvenile Huntington's Disease, but to help those who are struggling with this disease with financial aid.



## HD Genetics

<https://hdgenetics.com/>

HD Genetics understands that the decision to pursue genetic testing for Huntington's disease (HD) can be difficult. We offer you the ability to undergo genetic counseling and testing with a licensed HD genetics expert from the comfort & convenience of your own home! HD Genetics also offers options to test under a concealed identity for individuals who wish to test anonymously.



## Enroll-HD

<https://www.enroll-hd.org/>

Enroll-HD is a clinical research platform and the world's largest observational study for Huntington's disease families. It is a resource for the entire HD community, including families, clinicians, researchers, advocates, and anyone else who has a connection to or an interest in HD.



## HD BUZZ

<https://en.hdbuzz.net/>

Huntington's disease research news. In plain language. Written by scientists. For the global HD community.

HDClarity

HD Clarity

<https://hdclarity.net/>

A multi-site cerebrospinal fluid collection initiative to facilitate therapeutic development for Huntington's disease.

HD  
TrialFinder

HD TrialFinder

<https://hdsa.org/hd-research/hd-trial-finder/>

HD Trialfinder is a clinical trials matching service: a way for individuals with Huntington's disease, caregivers, healthy volunteers, and physicians to connect with current research studies. It includes an easy-to-use website and free call center staffed by trained HD clinical trial navigators

Honestly  
HD

Honestly HD

[HonestlyHD.com](https://HonestlyHD.com)





# GENETIC TESTING INFORMATION

**Thinking about getting tested?** Before proceeding with genetic testing for Huntington's disease, consider the potential psychological and emotional impact of the results, regardless of the outcome. Genetic testing may have implications not only for you but also for your family members. It is crucial to seek appropriate counseling and support throughout the process. Remember that genetic testing is a personal decision, and there is no pressure to undergo testing if you are not ready. It's best to discuss your concerns and questions with a healthcare professional who can guide you through the process and help you make an informed decision.

**Before you get tested:** *Please download this FREE packet for more information on IF getting tested is right for you.*

<https://hdsa.org/wp-content/uploads/2015/03/GeneticTesting.pdf>



# COMMON WAYS TO GET TESTED



## **Neurologist or Movement Disorder Specialist**

Neurologists and movement disorder specialists often have experience in diagnosing and managing Huntington's disease. They can help you understand the symptoms and whether genetic testing is appropriate for your situation.



## **Huntington's Disease Centers of Excellence**

Some specialized centers, known as Huntington's Disease Centers of Excellence, offer comprehensive care for individuals and families affected by the disease. These centers may provide genetic testing services as part of their care offerings.



## **University Hospitals and Medical Centers**

Many university-affiliated hospitals and medical centers have departments specializing in genetics and neurology, where you can access genetic testing for Huntington's disease.



## **National Institutes of Health (NIH) and Clinical Trials**

The NIH and other research institutions may offer genetic testing as part of clinical trials or research studies related to Huntington's disease. Participating in such studies may provide access to genetic testing.



## **Genetic Testing Laboratories**

Some commercial genetic testing companies offer direct-to-consumer testing for Huntington's disease. However, it is essential to exercise caution when using these services, as genetic testing for Huntington's disease can have significant emotional and psychological implications. Consulting with a genetic counselor or healthcare professional beforehand is strongly recommended.

# HOW MUCH DOES TESTING COST?

The cost of testing varies from center to center. Some centers are research facilities and will perform the test free of charge for those involved in their studies, some have sliding fee scales, and others charge anywhere from \$315 to \$1,500.

<b>Testing Centers</b>		
<b>Rhode Island</b>	<b>Massachusetts</b>	<b>Virtual/Other</b>
<p><b>Butler Hospital</b>            Movement Disorders Program            Providence, RI 02906  <a href="tel:401-455-6669">401-455-6669</a></p>	<p><b>HDSA Center of Excellence at Beth Israel Deaconess Medical Center</b>            330 Brookline Ave, Kirstein 2            Boston, MA 02115            Phone number to make appointments: 617-667-0519</p>	<p><b>HD Genetics</b>  <a href="http://hdgenetics.com">hdgenetics.com</a>  <a href="tel:877-434-3639">877-434-3639</a></p>
<p><b>Department of Neurology Rhode Island Hospital, Movement Disorders</b>            Providence, RI 02903  <a href="tel:401-444-6528">401-444-6528</a></p>	<p><b>HDSA Center of Excellence Huntington's Disease Testing Center, Massachusetts General Hospital</b>            114 16th Street, East Bldg. 114, Suite 201            Charlestown, MA 02129  <a href="tel:617-726-5732">617-726-5732</a></p>	<p><b>UCONN Health Center for HD</b> 10 Talcott Notch Road            Farmington CT 06520  <a href="tel:860-679-6775">860-679-6775</a></p>
	<p><b>Boston Medical Center/BU</b>            Boston, MA 02118            For an appointment: 617-414-4841</p>	<p><b>Albany Medical Center</b>            Albany NY, 12208  <a href="tel:518-262-5120">518-262-5120</a></p>

# REPRODUCTIVE GENETIC TESTING CENTERS



Rhode Island/Connecticut	Massachusetts
<p><b>Women and Infants Hospital</b> Prenatal Diagnosis Center 101 Plain Street 6th Floor Providence, RI 02905 <u>401-453-7510</u></p>	<p><b>Massachusetts General Hospital</b> 55 Fruit Street Boston, MA 02114-2696 <u>617-724-9009</u></p>
<p><b>UCONN Fertility</b> 2 Batterson Park road Farmington CT 06032 <u>844-HOPEIVF</u> <u>844-467-3483</u></p>	<p><b>BIDMC Pregnancy</b> 330 Brookline Avenue Boston, MA 02215 <u>617-667-0475</u></p>
	<p><b>Boston Children's Hospital</b> Maternal Fetal Care Center 300 Longwood Ave. Boston, MA 02115 <u>617-355-6512</u></p>
	<p><b>Boston IVF</b> 1 Liberty Square, Boston MA, 02109 <u>857-244-6750</u></p>

# HD-SPECIFIC PROVIDERS

## **PHYSICAL THERAPY**

---

### **Sarah Crandall Zoeller PT, DPT, NCS**

101 Main Street, Ste 101, Medford, MA 02155  
scrandall@partners.org  
Spaulding Rehabilitation Hospital - Medford  
781-391-7518

### **Lisa Walkin , PT MS GCS CEEAA**

ProCare Therapy Services  
480 Reservoir Ave.  
Cranston, RI  
401-270-2500

## **SPEECH THERAPY**

---

### **BrownHealth Rehabilitation Services**

765 Allens Ave, Suite 102  
Providence, RI 02905  
401-444-5418

### **BrownHealth Rehabilitation Services**

195 Collyer Street Suite 301  
Providence, RI 02906  
401-793-4080

### **Spaulding Outpatient Center at Kent Hospital | East Greenwich**

1351 South County Trail  
Building 2  
East Greenwich, RI 02818  
401-886-4650

### **Sargent Rehabilitation Center**

(up to age 22)  
800 Quaker Lane, Warwick, RI 02818  
401-886-6600

### **Aphasia Center**

MGH Institute of Health Professions  
2 Constitution Wharf  
Charlestown, MA  
[https://mghihp.formstack.com/forms/ipc\\_client\\_services\\_inquiry\\_form](https://mghihp.formstack.com/forms/ipc_client_services_inquiry_form)



# LEGAL ASSISTANCE MASSACHUSETTS



## **HYMAN DARLING, CELA**

Bacon Wilson, PC  
Specialty: Estate Planning  
33 State Street  
Springfield, MA 01103  
Tel: (413) 781-0560  
Fax: (413) 739-7740

## **MEREDITH H. GREENE, ESQ.**

Day Pitney LLP  
Specialty: Special Needs Trusts, Estate  
Planning, Guardianship, Conservatorship  
One Federal Street, 29th Floor  
Boston, MA 02110  
Tel: (617) 345 4622  
Fax: (617) 607 6033

## **KEN W. SHULMAN, ESQ.**

Day Pitney LLP  
Specialty: Estate Planning, Special Needs  
Trusts  
One Federal Street, 29th Floor  
Boston, MA 02110  
Tel: (617) 345-4789  
Fax: (617) 206-9357

## **DANIEL SURPRENANT, CELA**

Surprenant & Beneski, P.C.  
<https://myfamilyestateplanning.com>  
35 Arnold Street  
New Bedford, MA 02740  
Tel: (508) 979-0975

## **NEAL A. WINSTON, CELA**

Mulvena Winston, PC  
[neal@mulvenawinston.com](mailto:neal@mulvenawinston.com)  
2 Main Street, Suite 350  
Stoneham, MA 02180  
<https://winstonlg.com/>  
Tel: 781-288-4100  
Fax: 781-791-4606

## RHODE ISLAND

### **MARK B. HEFFNER, CELA**

Heffner & Associates

mheffner@hefflaw.com

615 Jefferson Boulevard

Warwick, RI 02886

Tel: (401) 737-1600.

Fax: (401) 737-1652

### **AMY STRATTON**

mail@MoonanStratton.com

4 Richmond Square, Suite 150

Providence, RI 02906.

(401) 272-6300

## HD EXPERIENCE

### **JONATHAN MACEDO**

macedo.jonathan@gmail.com

<https://kecheslaw.com/injury-attorneys/>

Phone: 508-500-1188

### **ALLISON BARTLETT, ESQ.**

abartlett@hdsa.org

Senior Manager, Disability Programs

HDSA

## OTHER LEGAL HELP

### **MA BAR REFERRAL SERVICE**

(866) 627-7577

### **RI BAR REFERRAL SERVICE**

(866) 627-7577

### **MA LEGAL RESOURCE FINDER**

<https://masslrf.org/en/home>

### **RI LEGAL SERVICES**

<https://rils.org/>

# SOCIAL SECURITY DISABILITY ASSISTANCE



## What if I become disabled due to my disease?

The HDSA has a lawyer on staff; she is the only one in the country who specializes in HD and applications for HD patients. Allison Bartlett, Esq - [abartlett@hdsa.org](mailto:abartlett@hdsa.org)  
It is a good idea to understand the process and what is needed BEFORE starting your application. A good first step can be to review the following and contact Allison:  
<https://hdsa.org/find-help/healthcare-and-future-planning/disability-benefits-and-hd-2/disability-support/>

- 1 The first step in apply for disability or federal aid is understanding the program that you need. The Social Security Administration has two disability programs which are federally funded. They are often confused because they have many similarities and some important differences. These programs are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).  
You can apply online: <https://www.ssa.gov/onlineservices/>  
Call: Toll-Free: 1-800-772-1213  
If need further assistance you can go to a local office. There are multiple IN PERSON locations throughout Massachusetts and RI;  
**follow the link to find an office close to your home.**  
<https://secure.ssa.gov/ICON/main.jsp#officeResults>
  - 2
-

## **Disability help guide for getting started:**

Adult: <https://www.ssa.gov/disability/Documents/Adult%20Disability%20Starter%20Kit%20508%20English%209.25.23.pdf>

Child: [https://www.ssa.gov/disability/disability\\_starter\\_kits\\_child\\_eng.htm](https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm)

### **Important things to include in your DISABILITY application to avoid being denied:**

Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security's standards for disability benefits. These conditions primarily include certain cancers, adult brain disorders, and a number of rare disorders that affect children. This initiative helps us reduce waiting time to reach a disability determination for individuals with the most serious disabilities.

Huntington's disease is also discussed in the Social Security Administration's "Blue Book" listing of disabling conditions in two different sections. The physical aspects of the disease are discussed in Section 11 (Neurological Disorders) under paragraph 11.17 (Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration). When an applicant is suffering primarily from mental or cognitive effects of Huntington's Disease, they may be instead evaluated according to the listing in paragraph 12.02 (Neurocognitive Disorders).

Below is information for compassionate allowance, please be sure to include this information when applying for disability. Impairment Evaluation Criteria Huntington's disease is on the Compassionate Allowance List and falls under the following section. This must be added to your application.

### **Section 11.00 – Neurological Disorders o 11.17 Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration.**

#### **For a complete how to guide visit this website:**

[https://health.ucdavis.edu/huntingtons/files/How\\_to\\_File\\_for\\_Social\\_Security\\_Disability\\_What\\_You\\_Need\\_to\\_know\[2\].pdf](https://health.ucdavis.edu/huntingtons/files/How_to_File_for_Social_Security_Disability_What_You_Need_to_know[2].pdf)

**Caution:** HD diagnosis is not enough to be considered disabled.

Social Security is evaluating your functional ability as it relates to your ability to work and care for yourself.

**Caution:** There is still a 24-month holding period of Medicare even if criteria is met for disability.

---





# THE LONG-TERM CARE CHALLENGE

Finding placement for a loved one in long term care that specializes in HD is limited. Please use the attached resource guide to provide to staff members and family to help them understand the disease. *Additionally, you can contact the local social worker for assistance in education the long-term care facility you chose for your loved one.*



MA/RI HDSA Social Worker  
Laura DiVeglia LCSW  
Ldiveglia@HDSA.org

Caregiver resource guide to provide to facilities: [https://hdsa.org/wp-content/uploads/2015/04/CaregiverGuide\\_Mid\\_Late\\_StageHD.pdf](https://hdsa.org/wp-content/uploads/2015/04/CaregiverGuide_Mid_Late_StageHD.pdf)

Search for HD facilities here: <https://hdsa.org/about-hdsa/locate-resources/>

Below is a list of long-term care facilities who report experience with HD patients.

*This is not an endorsement of any mentioned facilities; note that not all facilities take Medicaid.*

Facility	Address	Contact
Eleanor Slater Hospital (State Hospital)	2090 Wallum Lake Rd. Pascoag, RI 02859	401-567-5400
Tewksbury Hospital (State Hospital)	365 East St Tewksbury, MA 01876	(978-851-7321)
CareOne Lowell	19 Varnum St. Lowell, MA 01850	(978-454-5644)
Fresh River Healthcare	96 Prospect Hill Rd. East Windsor, CT 06088	860-623-9846
Incompass Human Services (group home)	Tyngsboro, MA	978-349-3000 (MA ABI MFP Waiver Only)
Western Mass Hospital (State Hospital)	91 E. Mountain Road Westfield MA 01085	(413-562-4131)

# ADVOCACY/RESEARCH

SIGN UP



Action &  
Advocate

[hdsa.org/advocacyhome/TakeAction/](https://hdsa.org/advocacyhome/TakeAction/)



Research  
Projects

[hdsa.org/hd-research/learn-about-hd-research/](https://hdsa.org/hd-research/learn-about-hd-research/)



Clinial  
Trials

[app.emergingmed.com/hdsa/home](https://app.emergingmed.com/hdsa/home)

## Additional Numbers To Get Involved

- Helpline: 800-345-HDSA (4372)
- National Office: 212-242-1968
- Email: [HDSAinfo@HDSA.org](mailto:HDSAinfo@HDSA.org)

## Advocate: HD Parity Act

The HD Parity Act will waive the two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI). Medicare's two-year waiting period is particularly devastating for people with HD.

<https://hdsa.org/about-hdsa/advocacy/huntingtons-disease-parity-act-2/>

## Disability Advocacy/Rights

- Disability Rights Rhode Island: [drri.org/](https://drri.org/)
- Disability Law Center - Boston: [www.dlc-ma.org/](https://www.dlc-ma.org/)
- Centers for Independent Living : Peer support, advocacy, info/resources, assessments
- Ocean State Independent Living (Rhode Island): [www.oscil.org/](https://www.oscil.org/)
- Independent Living Centers (Massachusetts, by location): [www.mass.gov/independent-living-centers](https://www.mass.gov/independent-living-centers)

# GRANTS & FINANCIAL ASSISTANCE

**All Ages**

**Children & Young Adults**

**Children with Medical Needs**

**Selma Schimmel Vital Grant**

[www.vitaloptions.org/assistance](http://www.vitaloptions.org/assistance)

**Ellie's Army**

[elliesarmy.org/apply-for-assistance/](http://elliesarmy.org/apply-for-assistance/)

**Guidance Medical**

[guidancemedical.org/](http://guidancemedical.org/)

**Aubrey Rose Foundation**

[aubreyrose.org/financial-assistance-for-families/](http://aubreyrose.org/financial-assistance-for-families/)

**Chive Charities**

[chivecharities.org/recipe](http://chivecharities.org/recipe)  
[nt](http://chivecharities.org/recipe)

**B Brave Foundation**

[bbravefoundation.org/](http://bbravefoundation.org/)

**United Healthcare**

**Children's Foundation**

[uhccf.org/](http://uhccf.org/)

**Oracle Health Foundation**

[oraclehealthfoundation.org/pediatric-grants](http://oraclehealthfoundation.org/pediatric-grants)



# LOCAL SUPPORT GROUPS

Group	Phone	Email
Beverly Mass Support Groups, Virtual	508-446-7705	<a href="mailto:mirtas.ulivi@gmail.com">mirtas.ulivi@gmail.com</a>
Tewksbury Support Group, Virtual	978-808-2995	<a href="mailto:csull22@gmail.com">csull22@gmail.com</a>
Newton Support Group, caregivers only. Virtual	978-808-2995	<a href="mailto:csull22@gmail.com">csull22@gmail.com</a>
Northampton Support Group, In-person	413-586-0627	<a href="mailto:afowlerpysd@comcast.net">afowlerpysd@comcast.net</a>

**Additionally, you can contact the local HDSA social worker for information on upcoming groups.**

MA-RI Social Worker Laura DiVeglia LCSW	508-446-7705	<a href="mailto:ldiveglia@hdsa.org">ldiveglia@hdsa.org</a>
--	--------------	--

# STATE PROGRAMS - CONNECTIONS TO SERVICES

Office of Rehabilitation Services - RI

[ors.ri.gov](http://ors.ri.gov)

Mass Rehabilitation Commission - MA

[mass.gov/orgs/massachusetts-rehabilitation-commission](http://mass.gov/orgs/massachusetts-rehabilitation-commission)

# BRAIN DONATION



The Harvard Brain Tissue Resource Center (HBTRC), established at McLean Hospital in 1978 and known as the Brain Bank, is a centralized resource for the collection and distribution of human brain specimens for brain research. The Brain Bank collects brain and tissue samples from across the United States and distributes them to investigators all over the world.

## **Daytime Contact (8:30am-5pm EST)**

Phone: 617.855.2400

Fax: 617.855.3199

Email: [HBTRC@mclean.harvard.edu](mailto:HBTRC@mclean.harvard.edu)

## **After Hours Contact (5pm-8:30am EST)**

Phone: 800.BRAINBANK (800.272.4622)

Fax: 617.850.8711

Email: [HBTRCoc@mclean.harvard.edu](mailto:HBTRCoc@mclean.harvard.edu)

# MEDICAL

## Medicaid-Funded Non Emergent Medical Transportation

Programs to assist patients with getting back and forth from medical appointments.

Rhode Island	Massachusetts
<p><b>MTM</b>  <a href="https://www.mtm-inc.net/rhode-island/">https://www.mtm-inc.net/rhode-island/</a></p>	<p><b>PT-1 (through GATRA or MART)</b>  <a href="https://www.mass.gov/info-details/get-a-ride-to-masshealth-medical-appointments">https://www.mass.gov/info-details/get-a-ride-to-masshealth-medical-appointments</a></p>

## Medication Savings & Copay Relief

<p><b>Good RX</b>  <a href="https://www.mtm-inc.net/rhode-island/">https://www.mtm-inc.net/rhode-island/</a></p> <ul style="list-style-type: none"> <li>• Compare coupon savings versus insurance copay (cannot use together with insurance)</li> <li>• Call your pharmacy to make sure they accept GoodRX coupons</li> </ul>	<p><b>CostPlus Drugs</b>  <a href="https://costplusdrugs.com">https://costplusdrugs.com</a></p> <ul style="list-style-type: none"> <li>• Compare savings versus insurance copay (cannot use together with insurance)</li> </ul>
<p><b>SingleCare</b>  <a href="https://www.singlecare.com/">https://www.singlecare.com/</a></p> <ul style="list-style-type: none"> <li>• Compare coupon savings versus insurance copay (cannot use together with insurance)</li> <li>• Call your pharmacy to make sure they accept SingleCare coupons</li> </ul>	<p><b>NeedyMeds</b>  <a href="https://www.needy meds.org/pap">https://www.needy meds.org/pap</a></p> <ul style="list-style-type: none"> <li>• Search for coupons for medications, as well as manufacturer discount applications</li> </ul>
<p><b>Patient Advocate Foundation</b> (HD Fund for All Insurances is Currently Closed but Will Reopen)  <a href="https://copays.org/funds/">https://copays.org/funds/</a></p>	<p><b>Healthwell Foundation</b> (HD Fund for Medicare is Currently Closed but Will Reopen)  <a href="https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/">https://www.healthwellfoundation.org/fund/huntingtons-disease-medicare-access/</a></p>

# MEDICAL

## Medically-Tailored Meal Delivery

### **Community Servings**

**<https://www.servings.org/>**

- Must be mostly homebound
- Massachusetts and Rhode Island - most areas
- Has Waitlist

# LOW INCOME CARE EQUIPMENT & GOODS

## **OLEY FOUNDATION**

Enteral Supply Donation Program  
[https://oley.org/page/Copy\\_Equipment\\_Exchange](https://oley.org/page/Copy_Equipment_Exchange)

## **DYSPHAGIA OUTREACH PROJECT**

Dysphagia Food Bank  
<https://www.dysphagiaoutreach.org/foodbank>

## **DME/REEQUIPMENT**

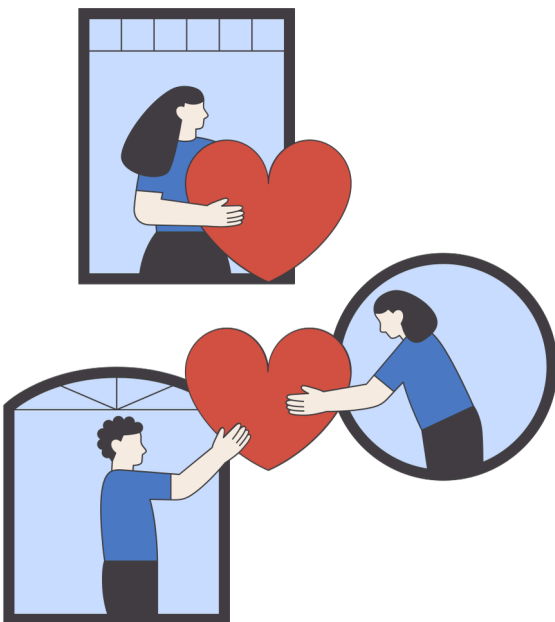
Durable Medical Equipment  
Massachusetts-based  
<https://dmereuse.org/>

## **GETATSTUFF**

Assistive Technology  
Massachusetts-based  
<https://getatstuff.massmatch.org/>

## **TECHACCESS RI**

Assessment and Device Loan  
Program  
Rhode Island Only  
<https://getatstuff.massmatch.org/>





Disclaimer: This information is not legal advice and is not preferential to any organization. HDSA MARI does not recommend any of these facilities, and proper research should be done prior to the use of these resources. This information is always subject to change. Please contact: [ldiveglia@hdsa.org](mailto:ldiveglia@hdsa.org) to add any additional resources or with comments on resources you would like to see included.