



Q1 2019
U.S. Transparency Charitable Contributions Report

Payment Recipient	Program Name	Amount (or Refund)
ALPHA 1 FOUNDATION	ALPHA-1 EDUCATIONAL MATERIAL	\$30,000.00
ALPHA 1 FOUNDATION	ALPHA-1 NATIONAL EDUCATION SERIES	\$75,000.00
ALPHA 1 FOUNDATION	ALPHA-1 WEBSITE	\$30,000.00
ALPHA 1 FOUNDATION	BUILDING FRIENDS FOR A CURE	\$145,000.00
ARIZONA HEMOPHILIA ASSOCIATION	ADVOCACY INITIATIVES	\$10,000.00
ARIZONA HEMOPHILIA ASSOCIATION	FUTURE LEADERS ADVOCACY PROGRAM	\$7,500.00
ASCRS FOUNDATION	OPERATION SIGHT	\$25,000.00
BLEEDING DISORDERS FOUNDATION OF WASHINGTON	ACCESS TO CARE INITIATIVE 2019	\$10,000.00
BLEEDING DISORDERS FOUNDATION OF WASHINGTON	ADVOCACY OUTREACH 2019	\$10,000.00
BLEEDING DISORDERS FOUNDATION OF WASHINGTON	INSURANCE NAVIGATION 2019	\$10,000.00
BLEEDING DISORDERS FOUNDATION OF WASHINGTON	LATINO EDUCATION WEEKEND 2019	\$2,500.00
BROWNPENNY FILMS LLC	STOP THE BLEEDING! 2019	\$400,000.00
BROWNPENNY FILMS LLC	THE 5TH ANNUAL TEEN IMPACT AWARDS	\$300,000.00
BROWNPENNY FILMS LLC	THE BLOODSTREAM PODCAST	\$150,000.00
CENTRAL CALIFORNIA HEMOPHILIA FOUNDATION	COLLEGE AND CAREER FAIR	\$500.00
CENTRAL CALIFORNIA HEMOPHILIA FOUNDATION	WORLD HEMOPHILIA DAY & 50TH ANNIVERSARY CELEBRATION	\$1,500.00
CHILDREN'S CANCER AND BLOOD FOUNDATION	2018 BREAKTHROUGH BALL	\$1,000.00
COMPREHENSIVE HEALTH EDUCATION SERVICES LLC	LEVERAGE: THE ULTIMATE INHIBITOR ADVENTURE	\$100,000.00
CONNECTICUT HEMOPHILIA SOCIETY	15TH ANNUAL CHS ALPINE WALK	\$3,500.00
EASTERN PENNSYLVANIA CHAPTER OF NATIONAL HEMOPHILIA FOUNDATION	ADVOCACY PROGRAM	\$9,500.00
EASTERN PENNSYLVANIA CHAPTER OF NATIONAL HEMOPHILIA FOUNDATION	ANNUAL MEETING	\$3,000.00
EASTERN PENNSYLVANIA CHAPTER OF NATIONAL HEMOPHILIA FOUNDATION	WOMEN'S RETREAT	\$5,000.00
EVERYLIFE FOUNDATION FOR RARE DISEASES	COMMUNITY CONGRESS MEMBERSHIP 2019	\$10,000.00
EVERYLIFE FOUNDATION FOR RARE DISEASES	COMMUNITY CONGRESS PUBLIC POLICY MEMBERSHIP 2019	\$10,000.00
EVERYLIFE FOUNDATION FOR RARE DISEASES	EVERYLIFE FOUNDATION FOR RARE DISEASES' 2019 NEWBORN SCREENING INITIATIVE	\$65,000.00
GATEWAY HEMOPHILIA ASSOCIATION	GHA'S 5K	\$500.00
GLAUCOMA RESEARCH FOUNDATION	PATIENT SUMMIT	\$10,000.00
GREAT LAKES HEMOPHILIA FOUNDATION	GLHF 2019 PATIENT ADVOCACY EDUCATION PROGRAM	\$6,000.00
HEMOPHILIA ASSOCIATION OF NEW YORK	DAY AT THE RACES	\$2,000.00
HEMOPHILIA ASSOCIATION OF NEW YORK	S.A.I.L - SELF ADVOCACY INDEPENDENCE AND LEADERSHIP YOUTH RETREAT	\$5,000.00
HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA	FAMILY EDUCATION WEEKEND	\$2,000.00
HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA	HACA TEEN ADVOCACY TASK FORCE	\$1,000.00
HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA	INFUSION CLASSES	\$1,750.00
HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA	STATE ADVOCACY DAY TRAINING /RICHMOND DAYS	\$3,000.00
HEMOPHILIA COUNCIL OF CALIFORNIA	2019 LEGACY SPONSORSHIP (PLATINUM LEVEL)	\$50,000.00



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HEMOPHILIA FEDERATION OF AMERICA	2019 HFA GENERAL ADVOCACY	\$30,000.00
HEMOPHILIA FEDERATION OF AMERICA	2019 HFA INSTITUTE	\$30,000.00
HEMOPHILIA FEDERATION OF AMERICA	2019 HFA PROGRAMS	\$395,000.00
HEMOPHILIA FEDERATION OF AMERICA	2019 HFA PROJECT CALLS	\$50,000.00
HEMOPHILIA FEDERATION OF AMERICA	2019 HFA SYMPOSIUM	\$83,000.00
HEMOPHILIA FEDERATION OF AMERICA	2019 POLICY & GOVERNMENT RELATIONS INTERNSHIP PROGRAM	\$35,000.00
HEMOPHILIA FOUNDATION OF GREATER FLORIDA	17TH ANNUAL THEATER EVENT	\$3,000.00
HEMOPHILIA FOUNDATION OF MARYLAND	MARYLAND ADVOCACY DAYS	\$5,000.00
HEMOPHILIA FOUNDATION OF MICHIGAN	HEMOPHILIA FOUNDATION OF MICHIGAN'S 2019 SPRINGFEST	\$22,500.00
HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS	BLEEDING DISORDERS AWARENESS DAY - MINNESOTA	\$3,000.00
HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS	HEARTS OF HOPE GALA FUNDRAISER	\$1,200.00
HEMOPHILIA FOUNDATION OF NORTHERN CALIFORNIA	HFNC'S ADVOCACY PROGRAM	\$7,500.00
HEMOPHILIA FOUNDATION OF OREGON	HFO 2019 ADVOCACY	\$5,000.00
HEMOPHILIA FOUNDATION OF OREGON	HFO PEAK TEEN PROGRAM	\$33,775.00
HEMOPHILIA FOUNDATION OF OREGON	YOUTH EFFECTIVELY TRANSITIONING TO INDEPENDENCE (YETI)	\$25,000.00
HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA	FAMILY INFO DAY	\$7,500.00
HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA	MEN'S RETREAT	\$2,500.00
HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA	SOCAL EMPOWERMENT FORUM	\$6,500.00
HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA	WOMEN'S RETREAT	\$2,500.00
HEMOPHILIA OF INDIANA	2019 BOWLING FOR BLEEDING DISORDERS	\$3,500.00
HEMOPHILIA OF INDIANA	2019 HEARTS FOR HEMOPHILIA GALA	\$5,000.00
HEMOPHILIA OF IOWA	COMMUNITY EDUCATION WEEKEND	\$4,000.00
HEMOPHILIA OF IOWA	HILL DAY	\$2,500.00
HEMOPHILIA OF NORTH CAROLINA	2019 ADULT RETREAT	\$2,500.00
HEMOPHILIA OF NORTH CAROLINA	2019 HEARTS FOR HEMOPHILIA CASINO NIGHT	\$5,000.00
HEMOPHILIA OF NORTH CAROLINA	2019 LEGISLATIVE DAYS	\$1,500.00
HEMOPHILIA OF NORTH CAROLINA	46TH ANNUAL HEMOPHILIA OF NORTH CAROLINA ANNUAL MEETING	\$4,000.00
IMMUNE DEFICIENCY FOUNDATION	GRASSROOTS ADVOCACY EDUCATION PROGRAM	\$255,000.00
IMMUNE DEFICIENCY FOUNDATION	IDF 2019 NATIONAL CONFERENCE	\$520,000.00
IMMUNE DEFICIENCY FOUNDATION	IDF ADVOCACY DAY	\$40,000.00
IMMUNE DEFICIENCY FOUNDATION	IDF CORE SERVICE PROGRAM	\$235,000.00
IMMUNE DEFICIENCY FOUNDATION	IDF FRIENDS COMMUNITY PAGE	\$25,000.00
IMMUNE DEFICIENCY FOUNDATION	IDF WALK FOR PRIMARY IMMUNODEFICIENCY	\$10,000.00
IMMUNE DEFICIENCY FOUNDATION	LIFE STAGES - IDF TEEN PROGRAM	\$73,000.00
IMMUNE DEFICIENCY FOUNDATION	PAYER EDUCATION PROGRAM	\$65,000.00
IMMUNE DEFICIENCY FOUNDATION	STAND UP FOR PII I IDF TEEN AND YOUNG ADULT ADVOCACY PROGRAM	\$55,000.00



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JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL CENTERS NETWORK (JMCM)	\$75,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL DIAGNOSTIC AND RESEARCH CENTERS	\$1,000,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION - AMA PHYSICIAN MAILING	\$25,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION - CORE SUPPORT	\$100,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION - NEW DOCUMENTARY FILM AND WORLDWIDE DISTRIBUTION	\$75,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION - WORLD IMMUNODEFICIENCY NETWORK (WIN)	\$50,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION - WORLD PRIMARY IMMUNODEFICIENCY WEEK (WPIW)	\$25,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	JEFFREY MODELL FOUNDATION KIDS DAYS	\$25,000.00
JEFFREY MODELL FOUNDATION INCORPORATED	NEWBORN SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCY (SCID) - GLOBAL PROGRAM	\$25,000.00
KENTUCKY HEMOPHILIA FOUNDATION	2019 KENTUCKY BLEEDING DISORDERS ADVOCACY PROGRAM	\$4,000.00
KENTUCKY HEMOPHILIA FOUNDATION	2019 VEGASVILLE EVENT	\$2,250.00
LA KELLEY COMMUNICATIONS INC	PARENT EMPOWERMENT NEWSLETTER	\$45,000.00
LA KELLEY COMMUNICATIONS INC	PEN'S INSURANCE PULSE	\$50,000.00
LA KELLEY COMMUNICATIONS INC	PROJECT SHARE	\$34,000.00
LA KELLEY COMMUNICATIONS INC	YOU	\$27,000.00
LONE STAR CHAPTER OF NATIONAL HEMOPHILIA FOUNDATION	2019 BLACK AND BLUE CASINO NIGHT	\$3,000.00
NATIONAL GAUCHER FOUNDATION INC	NATIONAL GAUCHER FOUNDATION CARE PROGRAM	\$500,000.00
NATIONAL HEMOPHILIA FOUNDATION	2019 ADVOCACY	\$5,000.00
NATIONAL HEMOPHILIA FOUNDATION	ACT INITIATIVE 2019	\$375,000.00
NATIONAL HEMOPHILIA FOUNDATION	BLOOD, SWEAT AND CHEERS GOLF TOURNAMENT	\$420.00
NATIONAL HEMOPHILIA FOUNDATION	COMMUNITY EDUCATION PROGRAMMING 2019	\$200,000.00
NATIONAL HEMOPHILIA FOUNDATION	COMPREHENSIVE CARE SUSTAINABILITY COLLABORATIVE (CCSC) 2019	\$625,000.00
NATIONAL HEMOPHILIA FOUNDATION	FUTURE LEADERS	\$2,500.00
NATIONAL HEMOPHILIA FOUNDATION	HAWAII OHANA LEGISLATION DAY	\$1,000.00
NATIONAL HEMOPHILIA FOUNDATION	INHIBITOR EDUCATION PROGRAMMING 2019	\$640,000.00
NATIONAL HEMOPHILIA FOUNDATION	INSURANCE AND REIMBURSEMENT CONFERENCE 2019	\$115,000.00
NATIONAL HEMOPHILIA FOUNDATION	NEBRASKA ADVOCACY DAY	\$1,000.00
NATIONAL HEMOPHILIA FOUNDATION	NHF ADVOCACY INITIATIVES 2019	\$450,000.00
*NATIONAL ORGANIZATION FOR RARE DISEASES (NORD)	GAUCHER'S DISEASE PATIENT ASSISTANCE PROGRAM	\$170,500.00
*NATIONAL ORGANIZATION FOR RARE DISEASES (NORD)	HUNTER'S SYNDROME PATIENT ASSISTANCE PROGRAM	\$400,000.00
*NATIONAL ORGANIZATION FOR RARE DISEASES (NORD)	SHORT BOWEL SYNDROME PATIENT ASSISTANCE PROGRAM	\$400,000.00
NEUROPATHY ACTION FOUNDATION	TARGETED DIGITAL EDUCATION CAMPAIGN AROUND MULTIFOCAL MOTOR NEUROPATHY - PHASE 2	\$65,000.00



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NEW ENGLAND HEMOPHILIA ASSOCIATION	NEHA ADVOCACY PROGRAM	\$15,000.00
NEW ENGLAND HEMOPHILIA ASSOCIATION	NEHA COUPLES' RETREAT	\$3,500.00
NEW YORK CITY HEMOPHILIA CHAPTER	REGIONAL EDUCATION ADVOCACY DEVELOPMENT FOR YOUTH (READY) TEEN RETREAT	\$2,300.00
NEW YORK CITY HEMOPHILIA CHAPTER	STATEHOUSE/ALBANY DAYS	\$4,690.00
NORTHERN OHIO HEMOPHILIA FOUNDATION	BLACK AND BLUE BALL	\$1,000.00
ORGANIZATION FOR RARE DISEASES INDIA	RACEFOR7: A 7KM WALK RUN OR CRAWL TO RAISE AWARENESS ABOUT THE 7000 RARE DISEASES	\$10,000.00
*PAN FOUNDATION	COST-SHARING ASSISTANCE FOR PATIENTS WITH HEMOPHILIA	\$500,000.00
*PAN FOUNDATION	COST-SHARING ASSISTANCE FOR PATIENTS WITH SHORT BOWEL SYNDROME PREMIUM	\$500,000.00
*PAN FOUNDATION	PREMIUM ASSISTANCE FOR PATIENTS WITH SHORT BOWEL SYNDROME	\$188,000.00
*PATIENT SERVICES, INC.	ACCESS (ADVOCATING FOR CHRONIC CONDITIONS, ENTITLEMENTS AND SOCIAL SERVICES)	\$150,000.00
*PATIENT SERVICES, INC.	ALPHA-1 ANTITRYPSIN DEFICIENCY PRIVATE PREMIUM ASSISTANCE	\$112,500.00
*PATIENT SERVICES, INC.	ALPHA-1 ANTITRYPSIN DEFICIENCY PUBLIC PREMIUM ASSISTANCE	\$112,500.00
*PATIENT SERVICES, INC.	ALPHA-1 PUBLIC COPAY ASSISTANCE	\$75,000.00
*PATIENT SERVICES, INC.	GAUCHER'S DISEASE PRIVATE ASSISTANCE	\$250,000.00
*PATIENT SERVICES, INC.	GAUCHER'S DISEASE PUBLIC ASSISTANCE	\$100,000.00
*PATIENT SERVICES, INC.	HEREDITARY ANGIOEDEMA PRIVATE ASSISTANCE	\$1,750,000.00
*PATIENT SERVICES, INC.	HEREDITARY ANGIOEDEMA PUBLIC ASSISTANCE	\$2,000,000.00
*PATIENT SERVICES, INC.	HYPOPARATHYROIDISM PRIVATE ASSISTANCE	\$262,500.00
*PATIENT SERVICES, INC.	HYPOPARATHYROIDISM PUBLIC ASSISTANCE	\$450,000.00
*PATIENT SERVICES, INC.	INHERITED AND ACQUIRED FACTOR DEFICIENCIES PRIVATE PREMIUM ASSISTANCE PROGRAM	\$250,000.00
*PATIENT SERVICES, INC.	INHERITED AND ACQUIRED FACTOR DEFICIENCIES PUBLIC PREMIUM ASSISTANCE PROGRAM	\$75,000.00
*PATIENT SERVICES, INC.	PRIMARY IMMUNE DEFICIENCY DISEASE PRIVATE PREMIUM ASSISTANCE	\$300,000.00
*PATIENT SERVICES, INC.	PRIMARY IMMUNE DEFICIENCY DISEASE PUBLIC PREMIUM ASSISTANCE	\$150,000.00
PROCARE PHARMACY LLC	2019 US HAEA NATIONAL PATIENT SUMMIT - IMAGINE THE POSSIBILITIES	\$92,000.00
ROCKY MOUNTAIN HEMOPHILIA AND BLEEDING DISORDERS ASSOCIATION	RMHBD A EDUCATION WEEKEND 2019	\$1,500.00
SAVE ONE LIFE INC.	2019 MISSION SUPPORT	\$30,000.00
SISTERS AND CAREGIVERS BLEEDING DISORDER NETWORK	A NIGHT OF MAGIC GALA	\$2,500.00
SJOGREN'S SYNDROME FOUNDATION	DRY EYE BROCHURE	\$15,000.00
SOUTHWESTERN OHIO HEMOPHILIA FOUNDATION	SWOHF ANNUAL EVENING OUT	\$1,000.00



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TENNESSEE HEMOPHILIA AND BLEEDING DISORDERS FOUNDATION	MEDICAL ALERT BRACELETS	\$600.00
*THE ASSISTANCE FUND	HEREDITARY ANGIOEDEMA (HAE) FINANCIAL ASSISTANCE PROGRAM	\$5,000,000.00
*THE ASSISTANCE FUND	HUNTER SYNDROME FINANCIAL ASSISTANCE PROGRAM	\$300,000.00
*THE ASSISTANCE FUND	HUNTER SYNDROME FINANCIAL ASSISTANCE PROGRAM	\$500,000.00
*THE ASSISTANCE FUND	PARATHYROID DISEASES FINANCIAL ASSISTANCE PROGRAM	\$250,000.00
*THE ASSISTANCE FUND	SHORT BOWEL SYNDROME FINANCIAL ASSISTANCE PROGRAM	\$4,000,000.00
THE CALLIOPE JOY FOUNDATION	THE CUPCAKE GALA	\$10,000.00
THE COALITION FOR HEMOPHILIA B	EDUCATIONAL PROGRAM AT 2019 SYMPOSIUM	\$5,000.00
THE NATIONAL ORGANIZATION FOR RARE DISORDERS	DISEASE STATE EDUCATION	\$40,000.00
THE NATIONAL ORGANIZATION FOR RARE DISORDERS	RARE DISEASE DAY 2019	\$25,000.00
THE OLEY FOUNDATION	TITANIUM LEVEL PARTNERSHIP	\$132,400.00
THE ZOE ROSE MEMORIAL FOUNDATION DBA PREEMIE PARENT ALLIANCE	INDUSTRY COUNCIL	\$10,000.00
UNITED HEMOPHILIA FOUNDATION	ADVOCACY EDUCATION AND TRAINING SEMINAR	\$1,500.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	ADVOCACY EDUCATIONAL BREAKFAST	\$2,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	ADVOCACY TRAINING	\$5,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	FAMILY EDUCATIONAL WEEKEND	\$2,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	MARCH COMMUNITY EDUCATIONAL EVENT	\$2,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	MEDICAL SYMPOSIUM	\$1,500.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	RED TIE AFFAIR	\$2,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	TEEN EDUCATIONAL DAY	\$2,000.00
UNITED VIRGINIA CHAPTER NATIONAL HEMOPHILIA FOUNDATION	WOMEN'S ADULT EDUCATIONAL RETREAT	\$4,000.00
WESTERN PENNSYLVANIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION	WPCNHF 2019 EDUCATION WEEKEND	\$4,000.00
WESTERN PENNSYLVANIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION	WPCNHF'S 6TH SEMI-ANNUAL CORNHOLE TOURNAMENT	\$1,000.00

*Report reflects updated data for Q1 2019 that was not previously captured