



STRENGTH



STRENGTH IN REJEARCH

STRENGTH
OF OUR COMMUNITY

STRENGTH
THROUGH ENGAGEMENT

STRENGTH
OF OUR VOICE

STRENGTH
IN PARTNERSHIPS

Message from the Board and CEO

As we reflect on the past year, both of us are filled with immense pride and gratitude for the incredible strides we have made together. The National Scleroderma Foundation remains a beacon of hope and a relentless force in finding a cure and improving the lives of those living with scleroderma.

In 2024, our community's voice resonated louder than ever. We witnessed the power of unity as our chapters brought people together for in-person education events, and we resumed some of our most cherished gatherings across the country. These moments of connection have been invaluable, allowing us to share stories of strength and resilience.

Our commitment to supporting individuals and families affected by scleroderma has never wavered. In 2024, Foundation support groups across the country hosted more than 450 meetings. Support groups provide peer-to-peer support that can significantly improve quality of life. These groups create a safe space for individuals to share lived experiences, reducing the isolation and mental health challenges that often come with chronic illness. The shared understanding among peers fosters a sense of community, helping members feel less alone and more empowered in managing their condition.

We also made significant progress in making clinical trials more accessible. Our partnership with Carebox provides an easy and effective way for individuals, caregivers, and healthcare professionals to search and match with clinical trials, bringing us closer to groundbreaking treatments.

Our advocacy efforts have yielded remarkable results. Once again, we secured the inclusion of scleroderma in the Department of Defense's Peer-Reviewed Medical Research Program. This achievement opens doors for researchers to compete for grants that will advance our treatment options for scleroderma.

In direct support of research, we have committed over \$34 million in investigator-initiated research grants since our founding. In the spring of 2024, seven researchers began work on their Foundation-funded projects, and our global webinar series continues to facilitate shared learning with nearly 500 participants annually.

As we look ahead to 2025 and beyond, our resolve remains steadfast. The National Scleroderma Foundation will continue to lead with integrity, advocating passionately on behalf of our community and facilitating medical

research that brings us closer to a cure. We are closely monitoring the landscape for issues that may impact our community. We will continue to maximize our impact on complex issues facing those living with scleroderma, their families, and support networks as well as the medical and scientific communities.

Together, we will navigate the challenges of the future, fostering a community where everyone can share openly and engage in ways that support them best. Thank you for your unwavering support and dedication to our mission.









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Mary J. Wheatley, IOM, CAE Chief Executive Officer

STRENGTH IN REJEARCH:

BY THE NUMBERS

REJEARCH GRANT PROGRAM



- New Investigator Awards
- 4 Established Investigator Awards
- Funded
 "High Impact"
 Research Grant
 Projects
- Total Active
 Research Grants
 in FY24

\$34,889,784 total committed by the Foundation to date

EXPANDED AND GROWING EARLY CAREER MENTOR PROGRAM



- 6 Pre-Doctoral Summer Fellowships Awarded
 - early career investigators in the Early Career Investigator Program
- 8 senior mentors and 6 emerging mentors involved in the Early Career Investigator Program

GLOBAL WEBINAR PROGRAM



609 Global Webinar attendees in FY24

29 Countries represented by attendees

STRENGTHENING THE FUTURE OF REJEARCH

The National Scleroderma Foundation's 2024 Class of Investigators



Ramadan Ali, PhD, University of Michigan Mark Flapan New Investigator Award

Mechanistic connections between NETs and scleroderma vasculopathy



Md Nurunnabi, PhD, The University of Texas at El Paso

New Investigator Award

Investigating nanoparticle enabled cell specific apoptosis induction and fibrosis treatment



Brendon Baker, PhD, University of Michigan

Debra Lurvey Memorial Research Grant • Established Investigator Award

Metabolic and epigenetic targeting of stromal cell-matrix crosstalk for reversing fibrosis in scleroderma



Mohammed Osman, MD, PhD, University of Alberta

Established Investigator Award

Evaluating a role for polysialic acid as a diagnostic, prognostic and therapeutic target in systemic sclerosis



Laura Polivka, MD, PhD, Cedars-Sinai Medical Center (Los Angeles)

New Investigator Award*

Exploring the pathogenesis of severe juvenile systemic sclerosis

*This grant is supported in part by the Marta Marx Fund for the Eradication of Scleroderma



Reshmi Parameswaran, MS, PhD, Case Western Reserve University

Established Investigator Award

BAFF CAR-T treatment for systemic sclerosis



Maria Teves, PhD, Virginia Commonwealth University

Walter & Marie Coyle Research Grant • Established Investigator Award

Advancing scleroderma treatment: a study using primary cilia as a therapeutic target



STRENGTHENING FUTURE CARE THROUGH REJEARCH

2023 Established Investigator Awardee's Groundbreaking Research Explores Connections Between Systemic Sclerosis and Cancer

Dr. Natalie Saini, National Scleroderma Foundation 2023 Established Investigator Awardee, is a co-author of groundbreaking research exploring the connection between systemic sclerosis and cancer risk.

The study reveals how inflammation and immune responses in systemic sclerosis may lead to DNA damage, driving mutations often seen in pre-cancerous tissues. Findings include increased mutation rates and unique signatures linked to cancer-like processes, providing vital insights into disease progression and complications.



THE FUNDING FROM THE NATIONAL SOLERODERMA FOUNDATION HAS ENABLED MY LAB TO ACTIVELY PURSUE SOLERODERMA RESEARCH. OUR FINDINGS DEMONSTRATE THAT THE LINK BETWEEN CANCER AND AUTOIMMUNE DISEASES MAY BE INCREASED BY SOMATIC MUTAGENESIS. BASED ON OUR WORK WITH THIS GRANT, WE ARE NOW WORKING TOWARDS OBTAINING AN NIH ROI GRANT TO FURTHER INVESTIGATE MUTAGENIC MECHANISMS IN SOLERODERMA.

- NATALIE SAINI, MSC, PHD MEDICAL UNIVERJITY OF SOUTH CAROLINA



Foundation-Funded Research Stands Strong

During these times of uncertainty, the National Scleroderma Foundation continues closely monitoring the landscape for issues that impact our community. While we continue to actively engage with elected officials to advocate for policies that increase access to care for people living with scleroderma, we also recognize that foundation-funded research is more important than ever.

2022 New Investigator Publishes Findings from Project Exploring Using MRI for Screening and Monitoring Systemic Scleroderma ILD

Dr. Peter Niedbalski has worked to develop new MRI methods that can see damage that is present in the lungs of people with scleroderma. These methods include a standard MRI method called "UTE MRI" that generates images somewhat like CT images as well as a novel method called xenon MRI that images how well the lungs are functioning. Xenon MRI shows that lung function is impaired in people with scleroderma—even those who have not been diagnosed with lung disease. The ultimate goal is to determine whether these MRI techniques could be used as screening tools for lung disease in people with scleroderma. Dr. Niedbalski thinks that xenon MRI, in particular, may be very sensitive to changes in lung function, and is hopeful that we will be able to use xenon MRI to track response to treatment in

people with scleroderma.



This work was published in June 2024 in the international journal, Magnetic Resonance in Medicine.

THIS GRANT, MY PARTNERSHIP WITH THE NATIONAL SOLERODERMA FOUNDATION, AND MY EXPERIENCE THUS FAR WORKING WITH PEOPLE WITH SOLERODERMA HAVE MOTIVATED ME TO FOCUS ON SOLERODERMA RESEARCH THROUGHOUT MY CAREER. MY HOPE IS THAT I WILL BE ABLE TO CONTINUE TO BE PART OF THIS COMMUNITY, WORKING TO IMPROVE THE LIVES OF THOSE IMPACTED BY SOLERODERMA.

- PETER J. NIEDBALJKI, PHD
UNIVERJITY OF KANJAJ MEDICAL CENTER REJEARCH INJTITUTE

Well-funded, groundbreaking research ignites discoveries and the development of life-saving treatments. This research happens in the academic lab and is then carried forward to clinical trials and more effective therapies.

The Foundation, which has committed more than \$34 million dollars to scleroderma research to date, will continue to lead the charge to ensure researchers have the support they need to build our pathway to new treatments and a cure.

We appreciate your continued support of this life-changing and life-saving work.

-Mary J. Wheatley, IOM, CAE | Chief Executive Officer

STRENGTH OF OUR COMMUNITY

2024 WAJ A YEAR OF GROWTH & NEW BEGINNINGS

The fiscal year 2024 was a banner year for many of our chapters. Long-time events made triumphant returns while new chapters hosted inaugural events.

Mid-Atlantic Chapter

The Mid-Atlantic Chapter proudly partnered with the University of Pittsburgh Medical Center to present its first in-person educational event hosted by the chapter since the start of the pandemic, marking an expansion of the chapter's educational programming.

Held at the Seven Springs Mountain Resort, the event featured renowned guest speakers such as Gastroenterologist Dr. David Levinthal, Pulmonologists Dr. Belinda Rivera LeBron and Dr. Kevin Gibson, Pediatric Rheumatologist Dr. Kathryn Torok, and Pulmonary Rheumatologist and Researcher, Dr. Robyn Domsic.

The event was made possible thanks to a beguest from Janice G. Singer.





Southeast Chapter

The Southeast Chapter teed off for its 11th Annual Kathleen Basile Memorial Golf Tournament at Hamilton Mill Country Club in Dacula, Georgia. Attendees participated in a great day of golf, a putting contest, and an appreciation reception and awards ceremony.

The event marked a return for a long-time fundraiser that had not been hosted since the beginning of the pandemic. Overall, it was a success for the Southeast Chapter. Since 2009, the proceeds for the event add up to more than \$100,000.

The return of the tournament is just the beginning for the growing Southeast Chapter which has also seen the return of its Atlanta *Stepping Out to Cure Scleroderma* walk and has more in the works in the new year.

West Coast Chapter

The West Coast Chapter hosted its inaugural *Stepping Out to Cure Scleroderma* walk in Napa California, in May. More than 140 people participated in the walk, raising more than \$36,000.

To make the weekend even more special, Ashley Barron, our celebrity ambassador, hosted a Meet & Greet with a special teal macaron from Bouchon Bakery, and performed a benefit concert at JaM Cellars Ballroom.

THIS WAS SUCH A SPECIAL DAY FOR OUR COMMUNITY IN NORTHERN CALIFORNIA TO COME TOGETHER, AND SPEND THE DAY TOGETHER, FROM THE WALK IN THE MORNING, TO OUR MID-DAY MEET-AND-GREET, CULMINATING WITH AN AMAZING BENEFIT CONCERT WITH ASHLEY BARRON. WE HAD THE OPPORTUNITY TO MAKE REAL CONNECTIONS AND I KNOW I CAME AWAY INSPIRED FOR THE FUTURE.

- MARY WHEATLEY, CEO





GROWING STRONGER: PACIFIC NORTHWEST CHAPTER

The Pacific Northwest Chapter hosted the 2024 National Scleroderma Conference in Bellevue, Washington. Now, it's using the momentum to plan an even bigger new year.

The Pacific Northwest Chapter of the National Scleroderma Foundation is thrilled to share some exciting upcoming events as we continue our mission to support those affected by scleroderma and raise awareness about this complex autoimmune disease.



In 2025, we're stepping up our efforts with two *Stepping Out to Cure Scleroderma* walks. Our first walk of the year, on Mother's Day Weekend, is particularly special as it marks our first walk in Seattle. This timing is especially significant as scleroderma disproportionately affects women, with approximately 80% of diagnoses occurring in women. We encourage everyone to join us in Seattle to support these incredible women and their families.

Our second *Stepping Out to Cure Scleroderma* walk will be a tribute to the remarkable Maria Rivelli. Maria was a cornerstone of our chapter, dedicating years of service as a board member, coordinating our annual fundraising walk, and serving as Vice-President, among other vital roles. Beyond her official duties, Maria was a cherished friend and an integral part of our community. Her spirit, strength, and unwavering dedication to our cause continue to inspire us all. We will deeply miss her, and this walk will serve as a celebration of her life and her enduring impact on the Pacific Northwest scleroderma community.

We are also delighted to announce the return of our in-person educational event after a long hiatus due to the pandemic. This essential event, in honor of Cheri Woo, a passionate advocate for scleroderma awareness and education who bravely battled the disease herself, will provide invaluable information and support to patients, families, and caregivers. This is our first in-person educational event since 2019, and we are eager to reconnect with our community and provide access to expert knowledge on managing this challenging condition.

We believe these events represent significant steps in our ongoing commitment to supporting the scleroderma community in the Pacific Northwest. For more information about these and other Pacific Northwest Chapter events, visit scleroderma.org/PacificNorthwestChapter.

STRONGER BECAUSE OF OUR COMMUNITY: BY THE NUMBERS

Stepping Out to Cure Scleroderma and Special Fundraising Events

NUMBER OF WALKS

24



TOTAL RAISED FROM SPECIAL EVENTS \$216,690

**TOTAL RAISED BY WALKS \$495,465





TOTAL EVENT PARTICIPANTS

2,877

TOTAL RAISED FROM BUILD YOUR OWN FUNDRAISERS \$265,447





STRONGER WITH KNOWLEDGE

The National Scleroderma Conference

The National Scleroderma Conference was held July 19-21, 2024, in Bellevue, Washington. 441 people registered for the event. Of those registered, 221 declared it was their first time in attendance, with 21 being diagnosed in the last year. The conference featured 48 sessions through our multi-modal conference offering.

SOME OF OUR MOST POPULAR SESSIONS ACCORDING TO OUR PARTICIPANTS INCLUDED:

- Opening Keynote Rebuilding: The Importance of our Scleroderma Community with Dr. Tracy Frech
- Nutrition and the Microbiome with Dr. Elizabeth Volkmann
- Calcinosis Management in SSc with Dr. Carrie Richardson
- Oral Care in Scleroderma with Dr. David Leader
- Stem Cell Therapies in Scleroderma with Dr. Ankoor Shah
- Cancer and Scleroderma with Dr. Laura Hummers
- Cosmetic Procedures in Scleroderma with Dr. Heidi Jacobe

OTHER CONFERENCE HIGHLIGHTS INCLUDE:

- Kids Get Scleroderma, Too! was filled with essential opportunities for those with juvenile scleroderma and their families.
- Friday night's KGS2 carnival included fun activities such as face painting, caricature artists, balloon animals, and much more.
- Annual Awards Luncheon celebrated the many contributions of our volunteers who are the backbone of our grassroots mission delivery efforts.
- Closing keynote session highlighting the many journeys of scleroderma with our panel of scleroderma warriors.

Continuing Medical Education

The National Scleroderma Foundation offers Continuing Medical Education (CME) and Continuing Nursing Education (CNE) as a vital tool in advancing awareness and understanding of scleroderma and its comorbid conditions among health care providers.

Because scleroderma is a systemic disorder, individuals living with scleroderma are typically under the care of multiple specialists in the course of disease management, depending on the particular organ system(s) affected by the disease (e.g. skin, heart, lungs, kidneys, digestive track, etc.). There is a great need to educate medical professionals on the various manifestations of scleroderma to foster quicker, more accurate diagnosis to enhance outcomes and quality of life.

The Foundation's CME and CNE programs provide continuing education credits for health care providers to learn more about this complex disease. The Foundation hosted two CME programs last year, Interstitial Lung Disease in Scleroderma and Pulmonary Arterial Hypertension in Scleroderma. These CME programs are available to healthcare professionals free of charge at https://scleroderma.org/cme/ for one year.







STRENGTH THROUGH HOPE

The National Scleroderma Foundation's HOPE Line (800-722.HOPE/4673) is a free service offering support for people living with scleroderma, caregivers, families and the public.

The HOPE Line has made a significant impact in 2024. The Foundation responded to nearly 500 requests for information and support through our HOPE Line via both telephone and email.

The HOPE Line is staffed from 8:30 a.m. – 5:00 p.m. ET, and callers can leave a voicemail after hours. All inquiries receive a response within two business days. Requests for information and support can also be emailed to support@scleroderma.org.

OUR TEAM HAS THE KNOWLEDGE TO GUIDE YOU THROUGH A VARIETY OF TOPICS:

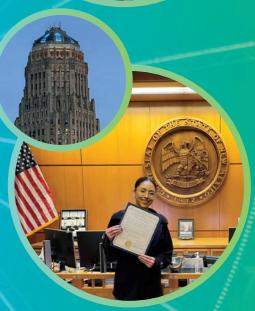
- Information about scleroderma
- How to get a diagnosis and what to do after you or someone you know receives a diagnosis
- Medical care needs
- Connecting with local chapters and resources
- Finding support groups and education programs
- Information about clinical trials











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STRENGTH OF OUR VOICE



The National Scleroderma Foundation's vision is to be a relentless force in finding a cure and improving the lives of people living with scleroderma. A key part of embodying that vision is supporting a network of advocates who work with local leaders and lawmakers to ensure scleroderma remains a research priority each year.

In addition to the tireless work of our community of volunteers who work to secure proclamations recognizing June as Scleroderma Awareness Month, the Foundation also works with the Health and Medicine Counsel to ensure lawmakers at the federal level are familiar with scleroderma and the ways they can support research to find a cure.

- In July 2023, the Health and Medicine Counsel attended the National Scleroderma Foundation's annual conference and made a presentation regarding the Foundation's advocacy activities. This was led by our HMC Representative Philip Goglas II, and key advocates, Evamarie Cole, Lucille Miller, and Courtney Caliendo.
- The National Scleroderma Foundation secured inclusion of "scleroderma" in the eligible conditions list for the Department of Defense (DOD)'s Peer-Reviewed Medical Research Program (PRMRP) for Fiscal Year 2024. This program allows our researchers to compete for grants within the DOD to advance understanding and treatment options for Scleroderma.
- In May 2024, the Foundation's CEO, Mary Wheatley, submitted Outside Witness Testimony to the House and Senate Appropriations Subcommittees on Labor, Health and Human Services, and Education and Related Agencies (LHHS). The testimony included funding recommendations for FY 2025 and key information about Scleroderma and NSF. The testimony also highlighted for the LHHS subcommittee a patient story that provided insight into the difficulties of living with Scleroderma.
- Throughout the first half of 2024, the Foundation conducted virtual
 meetings with key Congressional offices advocating once again for the
 inclusion of "scleroderma" in the PRMRP list for FY25, for which we were
 again successful. In addition to these virtual meetings, our community
 responded to action alerts and engaged with their elected
 officials to educate them about scleroderma.
- In April 2024, members of the National Scleroderma community traveled to Washington D.C. They participated as advocates for the Coalition of Skin Diseases (CSD). The Foundation is a proud member of the CSD.

We encourage anyone interested in learning more about advocacy and how to participate to reach out to us at advocacy@scleroderma.org.



STRENGTH FOR THE FUTURE

A Lasting Legacy

In 2024, The Rocky Mountain Chapter was honored with a special gift to establish the Ann Montera Endowed Scholarship Fund.

The fund was created to honor the legacy of a longtime leader of the Rocky Mountain Chapter, Ann Montera. Ann lived an extraordinary life. Despite a journey with scleroderma that stretched more than 50 years, she was determined to live a fruitful and happy life. Her determination led her to design and build six custom homes, manage a travel agency, start a successful catering business, work as a respected interior designer, become an accomplished artist, and travel to 67 countries. Most importantly, she defied medical odds by becoming a mother.

OUR HOPE IS THAT MORE PEOPLE LIVING WITH SCLERODERMA CAN GET THE EDUCATION AND SUPPORT THEY NEED TO LIVE A FULL LIFE LIKE ANN. OUR FAMILY IS HONORED TO PARTNER WITH THE NATIONAL SCLERODERMA FOUNDATION ROCKY MOUNTAIN CHAPTER TO SUPPORT THOSE LIVING WITH SCLERODERMA,



-THE MONTERA FAMILY

Each year, one person from the Rocky Mountain Chapter receives a scholarship to attend the National Scleroderma Conference through the Ann Montera Endowed Scholarship Fund. By attending conference, people living with scleroderma can get the education, resources, and support they need to live a full life like Ann.

Ann's legacy will never be forgotten. "She was my hero, and her determination and strength was focused not to beat the disease, but to provide information from her treatments that could be used on future patients," said her husband, Phil Montera, of almost 55 years.

We are so incredibly grateful for the Montera Family's commitment to keep Ann's memory alive through Ann Montera Endowed Scholarship Fund.

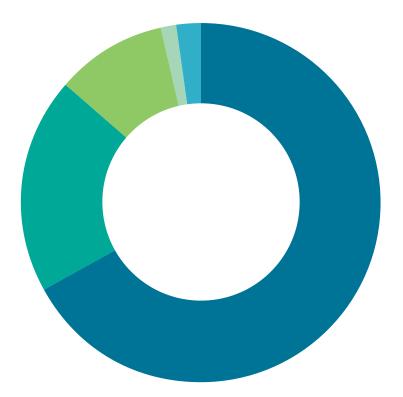
FINANCIALS

Statement of Activities for the Year Ended June 30, 2024

	Without Donor Restrictions	With Donor Restrictions	Total	%
REVENUE AND OTHER SUPPORT:				
Contributions	1,103,473	1,614,126	2,717,599	67%
Contributions Received from Affiliates	548		548	0%
Special Events (Net of Direct Benefit to Donor Cost)	788,371		788,371	19.4%
Bequests	406,093		406,093	10%
Returned Grant Awards	58,473		58,473	1.4%
Voluntary Research Contributions				0%
Investment Income Designated for Operations		91,252	91,252	2.2%
Net Assets Released from Restriction	1,718,372	(1,718,372)		0%
Total Revenue and Other Support	4,075,330	(12,994)	4,062,336	100%
OPERATING EXPENSES:				
Education and Support	2,782,391		2,782,391	40.3%
Research	1,929,049		1,929,049	28%
Total Program Services	4,711,440		4,711,440	68.3%
General and Administrative	1,172,886		1,172,886	17%
Fundraising	1,016,674		1,016,674	14.7%
Total Operating Expenses	6,901,000		6,901,000	100%
(Decrease) Increase in Net Assets from Operations	(2,825,670)	(12,994)	(2,838,664)	
NON-OPERATING ACTIVITIES				
Investment Income (Loss), Net	1,220,875	251,524	1,472,399	
Appropriation of Investment Income Designated for Operations		(91,252)	(91,252)	
Loss on Disposal of Property and Equipment	(522)		(522)	
Total Non-operating Activities	1,220,353	160,272	1,380,625	
(Decrease) Increase in Net Assets	(1,605,317)	147,278	(1,458,039)	
Net Assets, Beginning of Year	7,687,928	2,123,308	9,811,236	
Net Assets, End of Year	6,082,611	2,270,586	8,353,197	

Revenues

- Contributions
- Special Events (Net of Direct Benefit to Donor Cost)
- Bequests
- Returned Grant Awards
- Investment Income Designated for Operations



Expenses

- Education & Support
- Research
- General and Administrative
- Fundraising



STRONGER WITH PARTNERS

The National Scleroderma prides itself in collaborating with external partners for the advancement and increased visibility and awareness of scleroderma in rare and autoimmune disease spaces.

We hold official partnerships with the following organizations:













We have supported, signed on to letters and alerts, and collaborated more informally with many organizations to include:

- American College of Rheumatology
- Arthritis Foundation
- Arthritis National Research Foundation
- Autoimmune Association
- Carebox
- Childhood Arthritis and Rheumatology Research Alliance
- Global Genes
- Needy Meds
- Pediatric Dermatology Research Alliance

- PHAware Global Association
- Pulmonary Fibrosis Foundation
- Pulmonary Hypertension Association
- Research America
- Sjögren's Foundation
- Telehealth Access for America
- Value-Based Chronic Disease Collaborative
- Vasculitis Foundation

CORPORATE PHILANTHROPY

We are grateful for the generous support of our corporate donors. Our vision is to be a relentless force in finding a cure for scleroderma, and corporate partners are key to our success. The partners listed below help advance our shared mission and provide critical support for signature programs, like the National Scleroderma Conference and Stepping Out to Cure Scleroderma.

Gold





Silver









Additional Corporate Support Provided by

Genentech, Inc.

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Organizations

It is with tremendous gratitude that we recognize the following organizations, corporations and foundations that contributed \$1,000 or more in fiscal year 2023.

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RESEARCH	ADVOCACY	WALK	JTRENGTH	
SUPPORT GROUPS	VOLUNTEERS	∫TORI ⊝ ∫	ADVOCACY	MISSION
JTRENGTH		CLINICAL TRIALS	OUR VOICE	AWARENESS
COMMUNITY	норе	CONFERENCE	T O AL TALK	JOURNEY
EDUCATION	OURE	PARTNERS	JTRENGTH	

