

DNA, Family Reunification, and Pediatric Disasters: Lessons and Priority Research Agenda

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Action Collaborative on Disaster Research

National Academies Forum on Medical and Public Health Preparedness
for Disasters and Emergencies

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she/her/hers

Cuban-American

10-year-old daughter

8-year-old son



UCLA pediatrician

LA “juvie doc”

Ethnographer of DNA
bank for families
separated in the
Salvadoran Civil War

Overview

Reunification science

DNA for family reunification

Research agenda

Priorities for optimizing DNA
as a tool in disaster contexts



Reunification science

Family separation harms
children's health



Reunification science

Family separation should be **prevented** whenever possible, *and*

Reunification should occur **as quickly as possible**, when safe to do so



Reunification science

Family reunification is
under-researched



Reunification science

DNA can **reunify** children
with their families, *but*

Protocols need to be
developed

Preparedness is key!



Children's Rights & Family Reunification

The four domains in UN Convention on the Rights of the Child:



Developmental

Survival

Participative

Protective

Children's Rights & Family Reunification

The UN Convention on the Rights of the Child:

Article 8: Right to **identity**

Article 9: Right **not to be separated** from parents, unless in the best interest of child

Article 18: **Right to be raised by your parents**, if possible

Children's Rights & Family Reunification

The Right of **family**

The UN International Covenant on Civil and Political Rights
Article 23

The UN International Covenant on Economic, Social, and Cultural Rights
Article 10



REUNION

**FINDING THE DISAPPEARED CHILDREN
OF EL SALVADOR**



ELIZABETH BARNERT

WITH A FOREWORD BY
PHILIPPE BOUROSIS

Family reunification of El Salvador's "disappeared" children using DNA

Stages in the Continuum of Family Separation



Pre-disappearance

Disappearance

Separation - ongoing
ambiguous loss

Searching

Stages in the Continuum of Family Reunification



Identification

Reunion

Reintegration,
a lifelong process

Identification + Reunion + Reintegration = **FAMILY REUNIFICATION**

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Using DNA to reunify separated migrant families

By Elizabeth Barnert, Sara H. Katsanis, Ranit Mishori, Jennifer K. Wagner, Richard F. Selden, Diana Madden, Dan Berger, Henry Erlich, Kathryn Hampton, Andreas Kleiser, Alessandra La Vaccara, Thomas J. Parsons, Fredy A. Peccerelli, Mariana Herrera Piñero, Michael J. Stebbins, Patricia Vásquez, Curren W. Warf, Thomas J. White, Eric Stover, M. Veronica Svetaz

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Fears and perceived lack of tools should not be obstacles

Bosnian War
icmp.org



Image: ICMP

Guatemala's
Internal Armed
Conflict
fafg.org



Image: FAFG

Argentina's
"Dirty War"
argentina.gob.ar/ciencia/bndg



Image: The Guardian

El Salvador's
Disappeared
Children
probusqueda.org



Image: ProBúsqueda

A DNA-led database strategy for migrant family reunifications

The graphic delineates the parallel paths for DNA data collection for reunification of families separated as a result of the 2018 U.S. Zero Tolerance policy. NGO, nongovernmental organization; STRs, short tandem repeats.

Migrant children separated from families



- Third-party reunification team**
- Coordinates logs of outreach
 - Manages mouth swab collections
 - Coordinates NGO connections

Adults separated from migrant children



- United States-based NGOs/legal representatives**
- Coordinates location of children
 - Hold keys to names/locations



- Central American-based NGOs/legal representatives**
- Coordinates location of adults
 - Hold keys to names/locations

Deidentified mouth swabs

STR/rapid DNA analysis

Anonymous DNA data

Deidentified mouth swabs

STR/rapid DNA analysis

Anonymous DNA data



Children STR database



Intergovernmental organization

- Manages deidentified DNA data comparisons
- Retains deidentified DNA swabs for additional analysis, as needed
- Communicates matches to third-party team
- Removes from database DNA data from verified matches and destroys swabs

Adult STR database



- Notifies U.S. NGO of match to child
- Connects to Central American NGO/legal representative who can work with advocates for trauma-informed reunification

Third-party team



- Notifies Central American NGO of match to adult
- Connects to U.S. NGO/legal representative who can work with advocates for trauma-informed reunification

Oct 2020

Parents of 545 children separated at US border still can't be found



By [Priscilla Alvarez](#), CNN

Updated 10:55 PM ET, Tue Oct



CBS News / CBS Evening News / CBS Mornings / CTM Saturday / 48 Hours / 60 Minutes / Sunday Morning /

60 MINUTES

EPISODES - OVERTIME - TOPICS - THE TEAM

FAMILIES SEPARATED BY TRUMP ADMINISTRATION AT THE BORDER STILL WAITING FOR REUNIFICATION

Migrant children separated from their parents at the border were supposed to be reunited with their parents by the government within 30 days, according to an order from a federal judge. That was in 2018. Sharyn Alfonsi reports on the "ad-hoc" record-keeping that's led to continued separation.

2021

OCT 10

CORRESPONDENT

SHARYN ALFONSI

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FLIPBOARD



Oct 2021

Feb 2022

1,200 migrant children are still living with strangers. How is that not 'criminal'?

Opinion: How is it possible that the Biden administration still hasn't reunited as many as 1,200 migrant children with their parents?



[Elvia Díaz](#)

Arizona Republic

Published 4:01 p.m. MT Feb. 11, 2022

Ukrainian children are being separated from extended family at the U.S.-Mexico border

April 18, 2022 · 4:26 PM ET

Heard on [All Things Considered](#)



ADRIAN FLORIDO



Families were split up during Afghanistan evacuations — and are still not reunited

April 5, 2022 · 1:53 PM ET

RUCHI KUMAR



DNA Bridge is a consortium of **scientists** and **human rights experts** working to enable and promote the ethical and secure use of DNA data to reunify families separated by armed conflict, political repression, immigration, climate change, and disasters

Our goal is to **support the use of DNA analysis** in a **humane** manner to **reunify** families and **identify** missing persons around the globe



Overcoming barriers in a DNA-led approach

DNA only verifies close genetic relationships



Social networks, interviews, & review of legal documents can verify a range of relationship types

DNA collected for family reunification might be sought for comparison to criminal databases



DNA swabs and data collected for family reunification can be managed outside of governments

DNA can take months to process in a traditional lab



Rapid DNA technologies are portable, automated, and produce results in under 2 hours

DNA Bridge strategy

2018

Government-required DNA testing in
US-based, commercial laboratories
One-to-one testing strategy
Risk of revelation of relationships

DNA Bridge

DNA testing **outside of government control** with rapid DNA (or local labs)
Database in non-US-based, **intergovernmental** agencies
Only genetic relationships reported





**UNIVERSIDAD
GERARDO BARRIOS**
Líderes en Gestión del Conocimiento



DNA Bridge / Puente ADN

Data Management Strategy – *minimal data transfer*



DNA Bridge/Puente ADN partners with **field** collaborators to coordinate outreach and **DNA** collaborators to manage DNA specimens. DNA data are coded by the collaborators, then transferred securely to **ICMP** for database comparisons.

TYPES of DATA

| | |
|-----------------------|---------------|
| FAMILY NAMES | PHOTOGRAPHS |
| DISAPPEARED LOCATIONS | FAMILY TREES |
| DISAPPEARED DATES | DNA SPECIMENS |
| FAMILY CONTACT INFO | DNA DATA |
| IDENTITY DOCUMENTS | |

FIELD COLLABORATORS

- Provide referrals to families in need
- Manage personal data of separated family members
- Collect DNA specimens from family members
- Coordinate logs of outreach
- Code DNA specimens and maintain keys
- Maintain consent forms
- Record family testimony

DNA COLLABORATORS

- STR / rapid DNA analysis
- Upload DNA data to ICMP
- Maintain or destroy coded DNA specimens

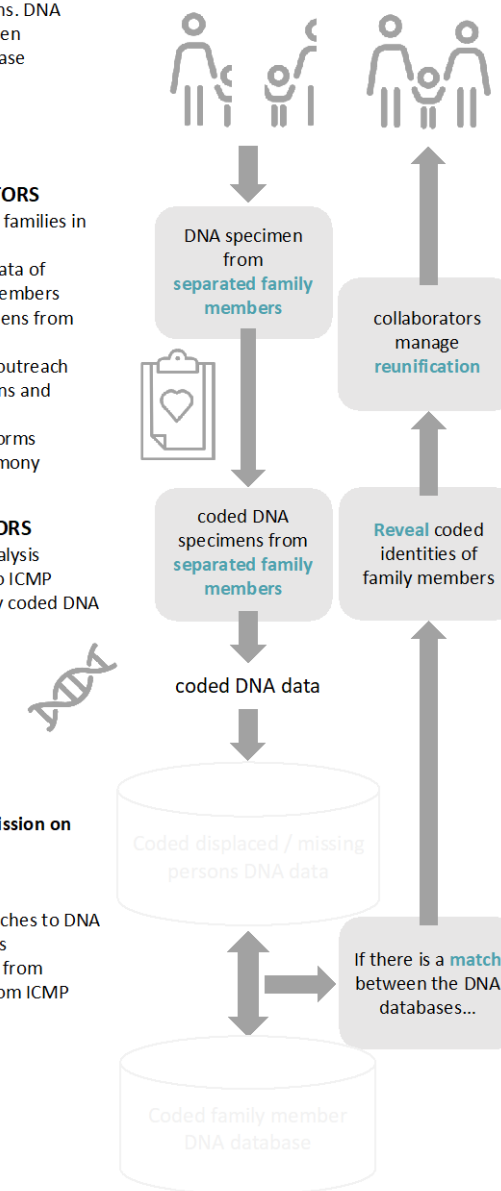
TYPES of DATA

| | |
|-----------------------|--------------------|
| CODED ID NUMBER | |
| DISAPPEARED LOCATIONS | CODED FAMILY TREE |
| DISAPPEARED DATES | CODED DNA SPECIMEN |
| | CODED DNA DATA |

ICMP

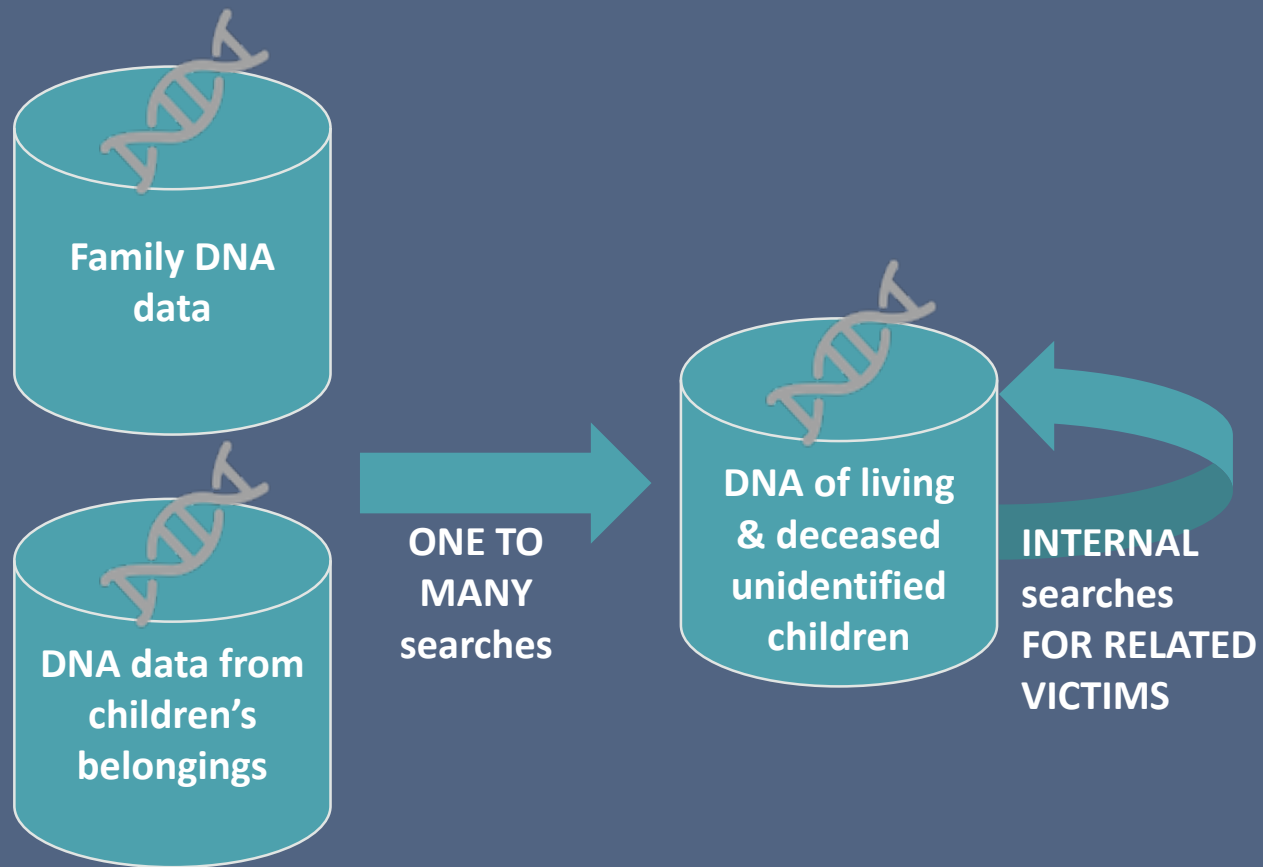
(International Commission on Missing Persons)

- Manages DNA data comparisons
- Communicates matches to DNA Bridge collaborators
- Removes DNA data from verified matches from ICMP DNA database



*DNA verification can provide **prompt, safe** family
reunification amidst the chaos of disasters*

Application of the DNA Bridge strategy to disasters



ON SITE

- Collect DNA from decedents, living children unable to ID themselves
- Conduct internal searches of victims database for related victims
- Genetic relatives present at the site supply sample for a one-to-many database search

OFF SITE

- Relatives of child may submit FRS for a one-to-many database searches
- Non-genetic or distantly related relatives may provide child's belongings for DNA reference samples

CLOSED DISASTERS



Manifest of victims

State and local government
+/- federal (FBI, FEMA)

*ADD: ~5 US regional labs, FEMA, make
FBI missing person database
accessible*

Mandate of victims:

International government(s)
Same model, intl
collaboration

ADD: global regional labs

DOMESTIC

INTERNATIONAL

No list of victims:

Same approach as above
Also need government
outreach to public to
develop list of missing
children/victims

No list of victims:

Same approach, intl
collaboration (especially if
unknown number of foreign
nationals)

OPEN DISASTERS



*Separations **harm families** and are **ongoing** across contexts*

***Every day separated** adds to the harms*

***Technologies exist** that can verify suspected matches and
reconnect children with their families*

Priority research agenda



Disaster Contexts

- Family reunification **needs** and **experiences** by context
- Optimal **role of DNA** and other biometric data by context

Priority research agenda



Processes to **protect rights** and **promote agency**

- Avoiding re-traumatization
- Fostering trust
- Navigating politics
- Balancing speed and accuracy

Priority research agenda



Protocols

- Informed consent
- Confidentiality
- Data security
- Stakeholder collaboration in support of families

No technology—including DNA analysis—can reunify all families. However, their inherent limitations are not adequate justification for avoiding their use to facilitate prompt reunification of children with their families.



The potential risk of privacy harms from DNA testing to reunify families is *not* an adequate justification for our collective inaction. The privacy risks can be readily mitigated – but the actual harms are compounding daily and must be addressed.

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International Commission on Missing Persons

Asociación Pro-Búsqueda de Niñas y Niños

Desaparecidos de El Salvador

Banco Nacional de Datos Genéticos (Argentina)

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