

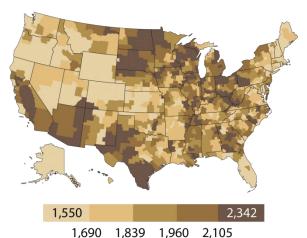
Overview of a Crisis of Care: The CACP Model

What is ESRD?

- End-stage renal disease (ESRD) is the complete or almost complete failure of the kidneys
- 7 of 10 new cases of ESRD are caused by diabetes or hypertension.1
- Treatment options are limited to hemodialysis, peritoneal dialysis or kidney transplant

ESRD in the U.S.

- 615,899 ESRD patients were receiving treatment in 20112
- 115,643 newly diagnosed ESRD patients in 20112
- Distribution of ESRD (adjusted prevalent rates of ESRD per million population)²



Source: USRDS, 2013 Annual Report

ESRD in Georgia

- 16,943 Georgians with ESRD were receiving dialysis treatment in 20123
- Georgia is part of ESRD Network 6, which comprises the largest patient and provider population in the U.S.

Racial & Ethnic Disparities

- Rate of new ESRD cases is 3.4 times higher among Blacks than Whites
- Hispanics are 1.5 times more likely to develop ESRD than non-Hispanics²

Treatment Costs

- \$49. 3 billion total Medicare and non-Medicare ESRD expenditures in 2011²
- ESRD patients make up 1.4% of Medicare population and drive 7.2% of the costs²

Treatment	Annual Medicare Spending/Person
Hemodialysis	\$87,945
Peritoneal Dialysis	\$71,630
Kidney Transplant	\$32,922

The Case of the Uninsured

- Estimated 48.8 million Americans are uninsured4
- Majority of uninsured ESRD patients are also undocumented immigrants, making them ineligible for Medicare
- Most uninsured ESRD patients is emergent dialysis guaranteed under **Emergency Medical Treatment and** Active Labor Act (EMTALA)
- Emergent dialysis is 3.7 times more costly than scheduled dialysis and yields worse outcomes5

A Growing Issue

- 11.7 million undocumented immigrants in the U.S.6
- 52% are from Mexico and Hispanics
- 60% concentrated in 6 states: California, Florida, Illinois, New York, New Jersey and Texas
- The influx of immigrants increases financial pressures on safety-net health care organizations

¹Centers for Disease Control and Prevention, http://www.cdc.gov/diabetes/pubs/pdf/kidney_factsheet.pdf

² U.S. Renal Data System, http://www.usrds.org/2013/slides/indiv/v2index.html ³ Southeastern Kidney Council, http://www.esrdnetwork6.org/utils/pdf/annualreport/Network%206%202012%20Annual%20Report%20Compressed.pdf

⁴ U.S. Census Bureau, http://www.census.gov/hhes/www/hlthins/data/incpovhlth/2012/Table7.pdf

⁵ Sheik-Hamad, D. et al.; Care for immigrants with end-stage renal disease in Houston: a comparison of two practices; Texas Medicine 103(4):53-58, 2007.

⁶ Passel, J; Population Decline of Unauthorized Immigrants Stalls, May have Reversed, Pew Research Center, 2013.



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Timeline of Changes in Medicare & Medicaid ESRD Coverage

1996: PRWORA

1972: Medicare ESRD program established

 denied all state and local public health benefits to undocumented immigrants

• States decide coverage

2006: Georgia Medicaid program ends dialysis coverage













1986: Omnibus Reconciliation Act

- prohibits use of Medicaid funds for undocumented immigrants
- established EMTALA

ruling classified dialysis as treatment for chronic, nonemergency conditions 2009: Grady Hospital closed outpatient dialysis clinic

Grady Memorial Hospital

- Closed outpatient dialysis clinic in 2009 and continues to close other clinics to reduce expenses
- Largest safety-net hospital and most advanced level-one trauma center in Georgia
- Provides care for Fulton & DeKalb County residents
- Became partially privatized in 2007 to reduce financial deficit

ARxC

- The Advocates for Responsible Care (ARxC) empowers individuals to achieve their maximum wellness with a strong voice as health care advocates, effectively reducing cultural incompetency and health care delivery disparity.
- Established 501(c)3 status and assumed responsibility as legal medical representatives of uninsured dialysis patients at Grady Memorial Hospital

- Reached out to over 28 states & 26 countries to bring awareness and garner support for the Dialysis Crisis
- Successfully extended scheduled dialysis for Grady's uninsured ESRD patients for five years and counting.
- Developing the Community Action Care Plan (CACP) to lead fight for more equitable care for uninsured ESRD patients
- Investigated path of legal status for the patients for more sustainable solution
- Continues to advocate on the behalf of the patients and to expand network of legal, academic, medical, and community partners

ARxC Dialysis Patients

- Dialysis Crisis Patient Characteristics:
 - 30 uninsured & undocumented patients from over 10 countries (i.e. Mexico, India, Nigeria, and many more)
 - Age Range: 28-77 years old
- Diversity of patients reflects expansive impact of inadequate ESRD care access



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- All the patients came to the U.S. as healthy young adults and developed ESRD while living and working in the US
- Some patients were medically eligible transplant candidates, but deprived because of costs. (A kidney transplant is a more effective and cost-efficient
- treatment option, but rarely considered in the U.S. for this population).
- As of August 9, 2014, all ARxC dialysis patients continue to receive scheduled dialysis treatment through a contract with Grady or an agreement with a private dialysis provider.



A New Dimension of Care

The Community Action Care Plan is a six-tiered approach to sustain regularly scheduled dialysis treatments for uninsured ESRD patients.

- 1. Secure trust of the patients and their families
- 2. Identify concerned parties and engaged stakeholders to discuss viable, compassionate, and community-based possibilities for sustaining dialysis.
- 3. Expose the severity of the crisis to the public by energizing the local, national, and international press to publish patient stories while facilitating direct access to patients for interviews, issued press releases, and press conferences.
- 4. Pursue legal action against medical facility, if necessary, to sustain care until an alternative source of care is secured.
- 5. Obtain support of local government to help facilitate negotiations between patients, providers and other stakeholders. Elect one advocate to serve as the patients' legal health care representative.
- 6. Organize an army of volunteers of students, patient advocates, and members of faith-based institutions and labor alliances to pressure key stakeholders to come to an agreement while petitioning private providers to accept patients "in kind."

This approach is not a long-term solution to the national crisis in care endured by uninsured ESRD patients.

It is critical that national policies be put into place to ensure uninsured ESRD immigrant patients receive the standard of medical care for their condition.