HHSC: Chronic Kidney Disease Task Force (CKDTF) Agenda, October 19th, 2020

1. Call to order, announcements and opening remarks. The meeting was convened by the Chair and a quorum was established.

2. Adoption of the July 29, 2020, meeting minutes. The minutes were approved as written.

3. Subcommittee workgroup reporting and collaboration: Updates from Task Force subcommittees

SUBCOMMITTEE A - Education & Prevention Danny Anchia

1. Early Education & Early Detection/screenings ◦ Data-driven and evidence-based ◦ Use sound methodology to track data and track progress

- Engage community for education and access to health screenings
    - Involve faith-based organizations to help with awareness and spread of educational materials
    - Partnerships with public and private entities such as TKF, SPKF, NKF, ANNA, TMF
- DSHS Community Health Workers (CHW) program (https://www.dshs.texas.gov/chw.aspx)
    - CHW Advisory Committee to develop CKD outreach plan
- Partner with hospital systems, state agencies, and other organizations to promote the NIH's National Kidney Month Toolkit and other available resources (https://www.niddk.nih.gov/health-information/community-health-outreach/national-kidney-month/toolkit).
- Partner with TEA-approved Coordinated School Health Programs to promote education in school systems (https://tea.texas.gov/texas-schools/health-safety-discipline/coordinated-school-health/approved-coordinated-school-health-programs)
    - Coordinated Approach to Child Health (CATCH) (https://catchinfo.org/modules/family-community/)
- Consider education opportunities in colleges, campus events, LGBTQ events, outreach to homeless, mobile clinics, food banks, minority and underserved communities, and other local/state/national leaders and organizations.

2. Public Awareness & Campaigns ◦ **Community engagement** ◦ Inclusive of different organizations and populations

- Assess and address health literacy
    - Low among patients with hypertension and kidney disease (Dageforde & Cavanaugh, 2013)
    - Low among patients > 65 yrs., racial/ethnic minorities, refugee/immigrant, low income, low education

- Utilize in person programs like the TKF's Live It Up and SPKF's Patient Symposium
- Revive and update the "Love Your Kidneys" public awareness campaign
    - Television
    - Cable and radio public service announcements (PSAs)
    - Posted Messages in pharmacies and grocery stores
    - Print ads in publications popular among African-American and Hispanic populations
- Research existing market channels and target demographics
    - Social media

3. Education & Awareness for HCPs ◦ CMEs, CEUs, Webinars, etc.

- Revive and update the "Save Their Kidneys" campaign for HCPs
    - Print ads in Texas Medicine and Texas Family Physician
    - Promoting the https://savekidneys.com/ website
    - Direct mailing to physicians and other health care providers in target markets
- Health care providers education
    - Include CKD as part of continuing education (CE) requirements
    - Department of State Health Services can offer presentations on CKD for its Grand Rounds Series
    - Texas Board of Nursing Newsletter
    - ANNA local and national chapters
- Coalitions of universities partnerships
    - Create a speaker list
    - Taped/recorded lectures on CKD
    - Conferences for providers
- Centralized Resource Center
    - Resources for professionals including videos, articles, research, studies, "It's Time Texas" short videos

4. Collaboration with local/state organizations

- DSHS, NIH, TEA, TKF, SPKF, NKF, TMF, ANNA, Texas Board of Nursing, Texas Medical Board, other Boards, colleges/universities, hospitals (including the VA), and specialty clinics (i.e., diabetes)
- Collaboration and coordination with Federal Agencies
    - CDC, CMS, NIH, the Indian Health Service, Department of Veteran Affairs, and Department of Defense all support direct care systems which serve populations with a high prevalence of, or at high risk for, CKD
    - Kidney Interagency Coordinating Committee (KICC) (https://www.niddk.nih.gov/about-niddk/advisory-coordinating-committees/kuh-icc/kicc)

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

  - Federal Chronic Kidney Disease (CKD) Matrix (https://www.niddk.nih.gov/about-niddk/advisory-coordinating-committees/kuh-icc/kicc/federal-ckd-matrix)
- Centralized CKD Resource Center sponsored by the State

5. Promote Modalities: transplant/organ donation and home/self-care

- Donation Subcommittee recommendations
  - Education, process improvement, deceased and living donation
- Adoption of CKD Change Packages
  - Improving Chronic Disease Self-Management by TMF (https://tmfnetworks.org/Networks/Community-Coalitions/Change-Packages/itg/CDCPCKD1)
  - Chronic Kidney Disease Change Package by the NKF (https://www.kidney.org/contents/chronic-kidney-disease-change-package)
- Adoption of Transplant and Home Change Packages
  - A Change Package to Increase Kidney Transplantation (https://www.esrdnetwork.org/sites/default/files/J.5%20Transplant%20Change%20Package_%203%20Month%20Extension.pdf)
  - A Change Package to Increase Home Dialysis Use (https://www.esrdnetwork.org/sites/default/files/J.4%20Home%20Dialysis%20Change%20Package_3%20Month%20Extension.pdf)

SUBCOMMITTEE B - Legislative Issues. Chronic Kidney Disease is a serious and urgent health problem that has become a serious Public Health Problem that a plan of action is needed. There will be times the Legislature Issues Committee will need to take issues to the Texas Legislature to advance public policy needs. Such needs as supporting public policy, education, and legislation to protect the health, civil rights and safety of people with kidney disease. Educate the policymakers about kidney disease, it's complications, and needed actions to assure access to quality healthcare. Another real concern is the over cost of CKD and ESRD which for Medicare alone is over $20 Billion annually.

Dialysis without following the same rules and regulations that in-center facilities and home programs have to follow.

Recommendation 1. There is a need for better regulation regarding provision of dialysis in certain settings (i.e. staff assisted dialysis in nursing homes, rehab, and LTACs, physicians' offices). Though these establishments are required to obtain a license by the State, they don't have to follow the same rules and regulations (State and Federal) that in-center facilities and home programs have to follow. There are a couple of statues that allow this to happen. All dialysis settings must meet the same safety and quality standards set forth by CMS and current State rules and regulations.

Recommendation 2. A need for State Resource Center - as this would be a huge program it would cover many steps to completion. Starting with the development of a flow chart to set forth the steps to becoming a State Resource Center, which would include information for Detection, CKD, ESRD, and Transplantation, and all other frequently asked questions.

SUBCOMMITTEE C - Treatment

Recommendation 1. CKD 1-5 patients in Texas, how do we identify everyone?

- Emphasize patient empowerment when screening
- Start with dialysis patients (60-70K) and patients who have been transplanted and contact family members
- Kidney screening (NKF Dallas, Houston, TKF: SA, 42 south Texas counties, South Plains Kidney Foundation North Texas)
- CKD5D (ESRD Network)
- Medicare data (by law to report eGFR)-can get data from Medicare/Medicaid, identify geographic regions with high prevalence,
- Proteinuria-automatic referrals (ECHO system in NM), guidelines to large hospital systems
- Electrolyte abnormalities often associated with CKD (i.e. hyperkalemia, met acidosis)
    - Emphasize cost to Texas as CKD progresses

Recommendation 2. Education-management of CKD for primary care, staff (SW, NP, PA, tech)

- Social determinants of health quality for CKD and ESRD
- Guidelines and protocols—best practice for CKD, cost of medications (SGLT2 inhibitors)
- Patient/staff empowerment—common ground, community centers (bike clubs, YMCA, YWCA), nonprofit groups, promotora, health days, churches and mosques, temples, flea markets. Teaching on food. Follow up with trainers. Presence, nephrology fellows, medical students/nursing students. Connect with academic training programs. Use adaptive/iterative learning approaches guided by data
- Telehealth opportunity-shift care to home, telenephrology
- Primary care to pay attention to albuminuria, proteinuria, metabolic acidosis, potassium

Recommendation 3. Trial network and registry of all patients. Emphasize diet, lifestyle and patient empowerment in clinical trials. Adaptive and pragmatic clinical trials. Messaging will be key

- CKD-Clinical trials on
    - diet, lifestyle, exercise,
    - telemedicine,
    - therapeutics
- HD- Clinical trials to focus on

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

  - Training and coaching-home HD in center
  - Quality hemodialysis, Transplant awareness
  - Self-care in center dialysis
- PD- clinical trials on
  - Dextrose effect in PD
  - Quality of life PD, Transplant awareness
  - Implantable artificial kidneys

This could be a good place for a dietician requirement recommendation.

SUBCOMMITTEE D - Early Detection/Comorbidities

Recommendation 1. Promote early detection of chronic kidney disease and the aggressive treatment of associated comorbidities (HTN, DM, Obesity, CVD) through education of healthcare providers including the offering of CME and CEUs and provider toolkits. Work with organizations such as the Texas Medical Association, Texas Academy of Family Physicians and similar groups to include the topics of Early Detection of CKD and Management of Comorbidities in their educational curriculum and seminars.

Recommendation 2. Support legislation to protect the health and safety of people with chronic kidney disease. Collaborate with Rita Littlefield's subcommittee to draft a proposal and recommendations to promote a Texas Kidney Resource Center for the residents and healthcare providers in our state.

Recommendation 3. Partner with AHA, TKF, NKF and ADA for community outreach and screenings. Focus on social determinants of health by addressing issues of food insecurity, transportation to appointments, and access to affordable medications to improve overall health outcomes.

Recommendation 4. Leverage relationships with the nurses in ANNA to assist with outreach and screenings utilizing their network and chapters throughout the state. Collaborate with the TX Quality Improvement Network, TMF to assist in working with hospitals and the CKD CMS improvement activities.

Recommendation 5. Promote email distribution, clinical and community-based educational programs, events and resources to improve the understanding detection and management of chronic kidney disease.

SUBCOMMITTEE E - Living Donation and Transplantation

Recommendations

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

Education
Coordinate donation and transplant education with other Task Force activities and recommendations

Professional Education
- Early diagnosis, early referral and goal of pre-emptive transplants
- Early identification of living donors and live donor options such as exchange programs and live donor registries

Patient Education
- Aids to identify and request living donation
- Availability of financial assistance programs
- Safety, risks and transplant priority for prior donors

Process Improvement
Management of early Stage 1, 2 or 3 chronic kidney disease
- Screening of high-risk populations
- Patient education (92% of early stage patients may not be aware of diagnosis)
- Maintenance of renal function to avoid progression

Creation of a Central Resource Center for kidney disease, donation and transplantation
- Public, Patient, Donor and Professional Information sections
- Links to resources

Deceased Donation
Improve collaboration between the three Texas OPOs
- Share best practices and develop state-wide activities and initiatives

Provide additional opportunities to register donation desire
- Drivers license, Donate Life Registry optimization
- Add donor option to hunting and fishing license, state park card

Promote donation as part of other state programs
- PSA spots for radio or television
- Website pop-ups or scroll spots
- Inserts in state mail-outs

Living Donation
Promotion and education regarding advantages of live donation
- Avoidance of dialysis, better outcomes, cost savings

Removal of financial dis-incentives for donation

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

- Benefits available from existing sources: National Living Donor Assistance Program, Payor benefits for donors, e.g., United Health Care donor assistance
- Paid time off for donation
- Living donation should not be an exclusion for future insurance coverage

Improve patient insurance coverage

- All health care plans should cover living donor kidney transplants
- Provision of life and disability coverage specific to donation

Post-Donation and Post-Transplant
Deceased donor family recognition

Living donor recognition and protections

- Maintain insurability without penalties for life and health coverage
- Employment safeguards to prevent job loss

Transplant recipient support to avoid graft loss

- Texas Kidney Health program and medication assistance
- Support for long-term immunosuppression coverage
- Other state programs that might benefit recipients

Recommendations for Report to the Governor. The Task Force zeroed down to the top ten recommendations. The Chair stated that the recommendations not adopted could be included in future reports.

Task Force Member Comments and Discussion:
The Chair stated that there are areas where recommendations can be developed that incorporate the discussion and thoughts of the Task Force.

Three areas stand out: education and prevention measures; public awareness and complaints; and education and awareness for health care professionals that touches other committees.

The need for a Centralized Resource Center was heard from the different groups and this could accommodate many recommendations. This would be the backbone.

A Centralized Resource Center is essential for people with renal disease so there is information at the patient level.

A Centralized Resource Center will lower the costs related to the disease.

Where are we envisioning this resource center to be? It should be in the Texas Health and Human Services Commission. They already have a kidney website.

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

Recommendation 1: Establishment of a Centralized Resource Center within HHSC (DSHS) and include sub-categories supporting early detection and intervention, monitoring and education.
There is a need for a clinical trial network and registry.

Patient empowerment focus would be important.

There is an absence of minority communities in the clinical trials.

We need more nephrologists. A Clinical Research Network will serve as a place to encourage younger physicians to join the field. We also need to attract more nurses knowledgeable about CKD.

Recommendation 2: Establish a Clinical Trial Network
The need for regulatory consistency was the first recommendation by the Legislative Committee. The main issue is that there are two statutes that allow several entities to operate without dialysis regulation. There is no oversight on training, or the way services are provided. This becomes a patient safety issue.

The need for physicians to see the patient twice a month becomes an issue. Telehealth is not allowed without an emergency rule.

Texas has been slow to make these kinds of changes. Third-party providers will likely to hire lobbyists.

ESRD/CKD experts should determine how the statutes should be resolved.

Recommendation 3: Provide Better Regulation for Common Standards for Dialysis Across Facility Types. Experts Will Define Those Common Standards.
(Other recommendations were implied but were not clearly articulated.)

CKD issues can be addressed in some of the earlier recommendations.

There is a lot of crossover that can be managed with more succinct language.

There is a common theme on education.

Donation preferences can be addressed through a broader use of state licenses.

Making recommendations that increase donations and provide motivation for donations and salary reimbursement for kidney donors.

807 BRAZOS ST, SUITE 607, AUSTIN, TX 78701 TEL: 512-708-8424, WWW.THBI.COM

There has to be coordination between the state and the federal government.

The Chair discussed some common themes that the Chair and subcommittee chairs will work on to develop a final list of recommendations:

- Centralized resource center
- Clinical Trial Registry
- Common standard for dialysis
- Donation recommendations will focus on deceased and living donations and making a kidney donation to last a lifetime. (Reimbursement for lost wages and worktime remains a sticking point.)

The Chair and vice chairs will distill these points into some written logic to distribute the workload a bit. This would allow the development of a report in the next four weeks. Position papers on each recommendation will be developed.

MOTION: *Authorize the Chair and vice chairs to accommodate the discussion from the day and draft a (succinct) report and recommendations based on that discussion - prevailed.*

4. Adoption of bylaws. Tabled.

5. Public comment. No public comment was offered.

6. Committee feedback and planning for next meeting. No feedback or planning comments were received.

7. Adjourn. The next meeting is December 14th. There being no further business, the meeting was adjourned.

***