



University of Puerto Rico  
Medical Sciences Campus  
School of Medicine  
Department of Pediatrics



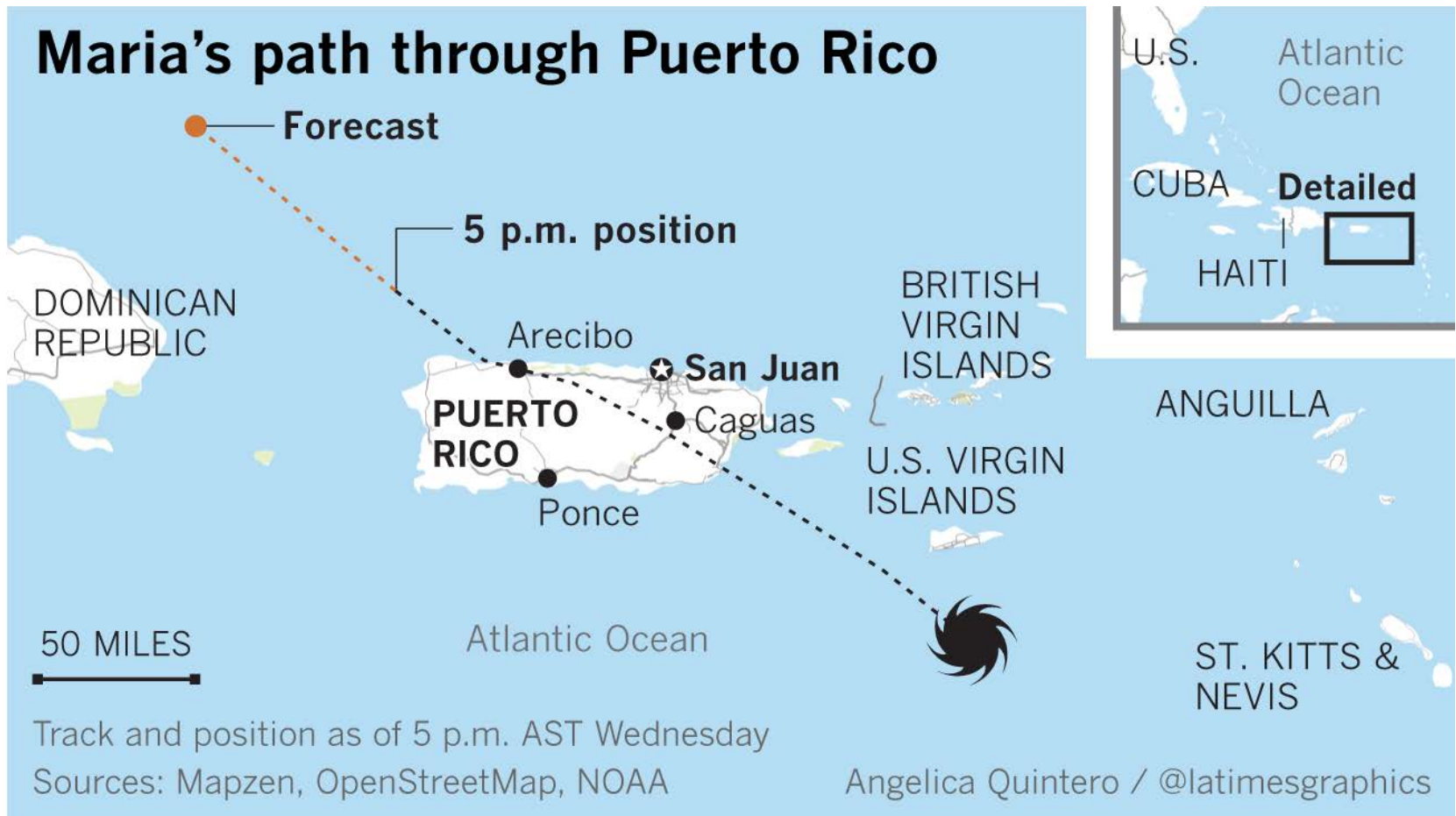
# Hurricane Maria: Experience of the Puerto Rico Newborn Screening Program



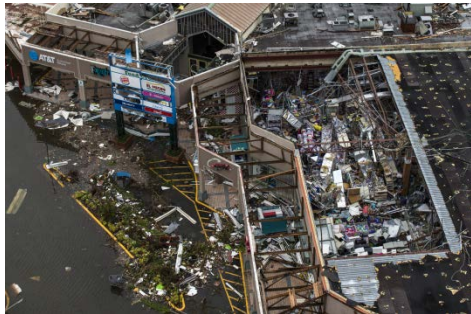
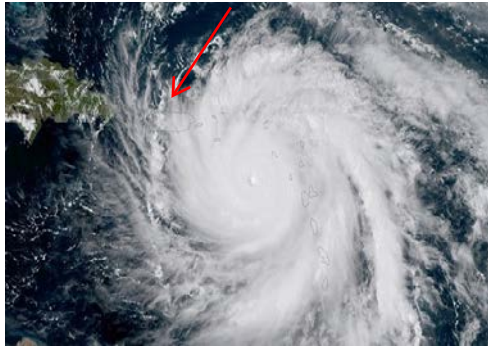
**Dr. Sulay Rivera-Sánchez**  
Associate Director

January 29, 2018  
STFU Webinar

# Hurricane Maria: September 20, 2017



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# NBS Program Preparation for Hurricane Maria

- All the equipment was covered and if possible they were placed over counters (not left on floor).
- Equipment was turned off (if possible), disconnected and/or protected with a battery system.
- Materials and equipment next to windows were moved to another area.
- The keys of our rooms were provided to the Administrative/Security staff of the hospital in case of an emergency. Instructions were also provided about areas with possible roof leaks or in which water could enter through the windows.
- Instructions were given to the staff to do back up to important files
- We evaluated all our pending patient cases.

# Impact on PR NBS Service

September 2017

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30



Localized in the University Pediatric Hospital at San Juan Medical Center

## 1. Infrastructure

The building and our facilities (cement-based) suffered minor damages:

- An old air conditioner fell from the wall.
- Some water came in through the windows.

# Impact on PR NBS Service

**We were lucky!!!**

**Water**

**Power (no stable)**

**Internet (no stable)**

**One telephone line (with some occasional problems but working)**

**Health information system**

**Reduced personnel available**

**No major damages so we were ready to continue saving babies!!**



# Impact on PR NBS Service

## 2. Sample collection and delivery to NBS laboratory

- ❖ During the storm, the majority of the 69 hospitals in our island were left without electricity or fuel for generators.
- ❖ Communication with the majority of hospitals was lost.
- ❖ Many roads were obstructed.

# Impact on PR NBS Service

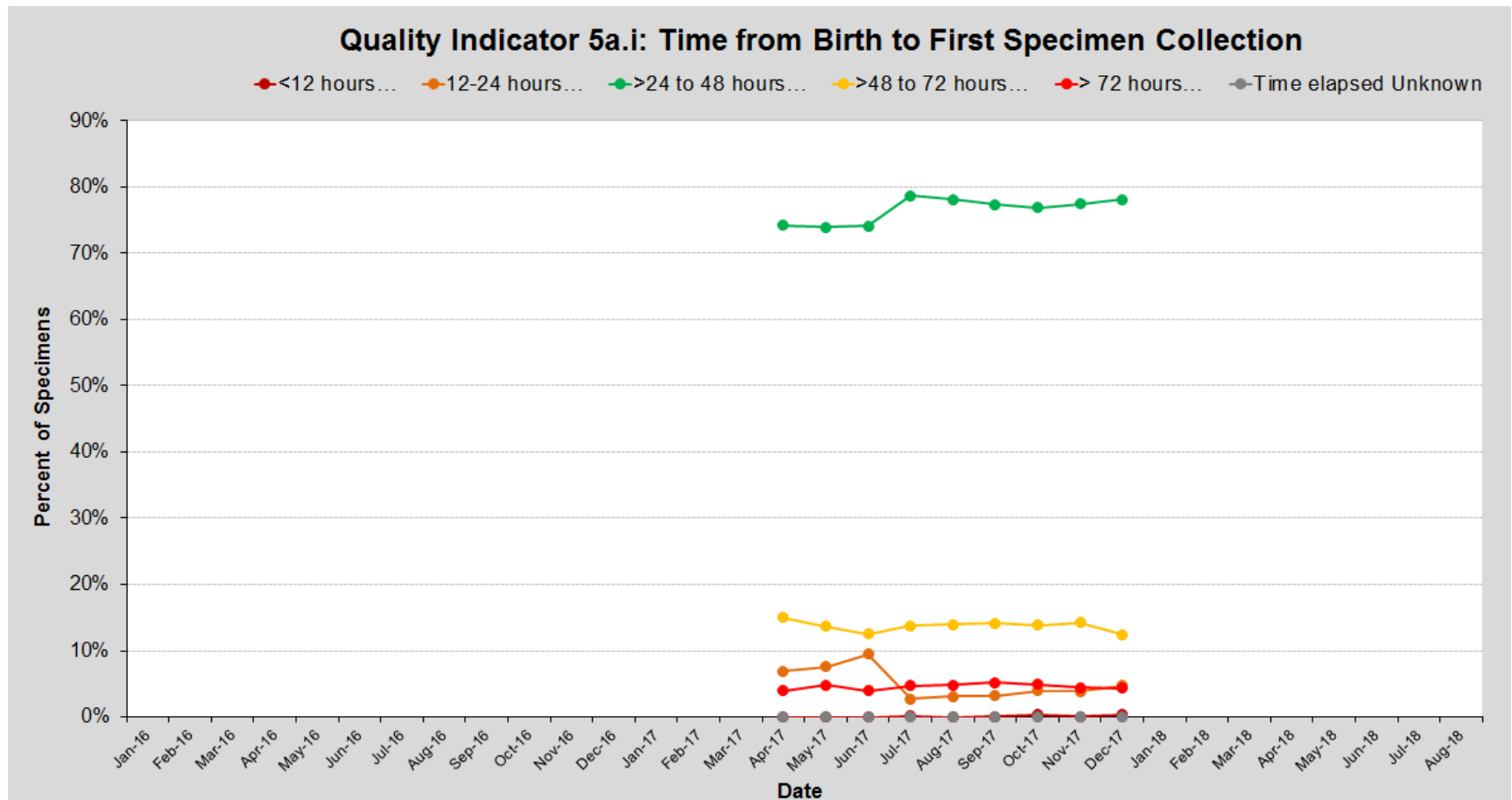
## 2. Sample collection and delivery to NBS laboratory

- ❖ **Messengers from hospitals started to come that week to bring samples.**
  - **No sample rejected**
  - **Additional Contact Information was requested to hospitals**
  - **A letter was sent to hospitals with instructions for sample collection and storage**
  
- ❖ **Calls were made to the hospitals to inform that the NBS Program was operational and that we were waiting for the samples**
  
- ❖ **CDC Hurricane Response Division contacted us and we reported them the hospitals that were not sending samples to evaluate their status.**



# Impact on PR NBS Service

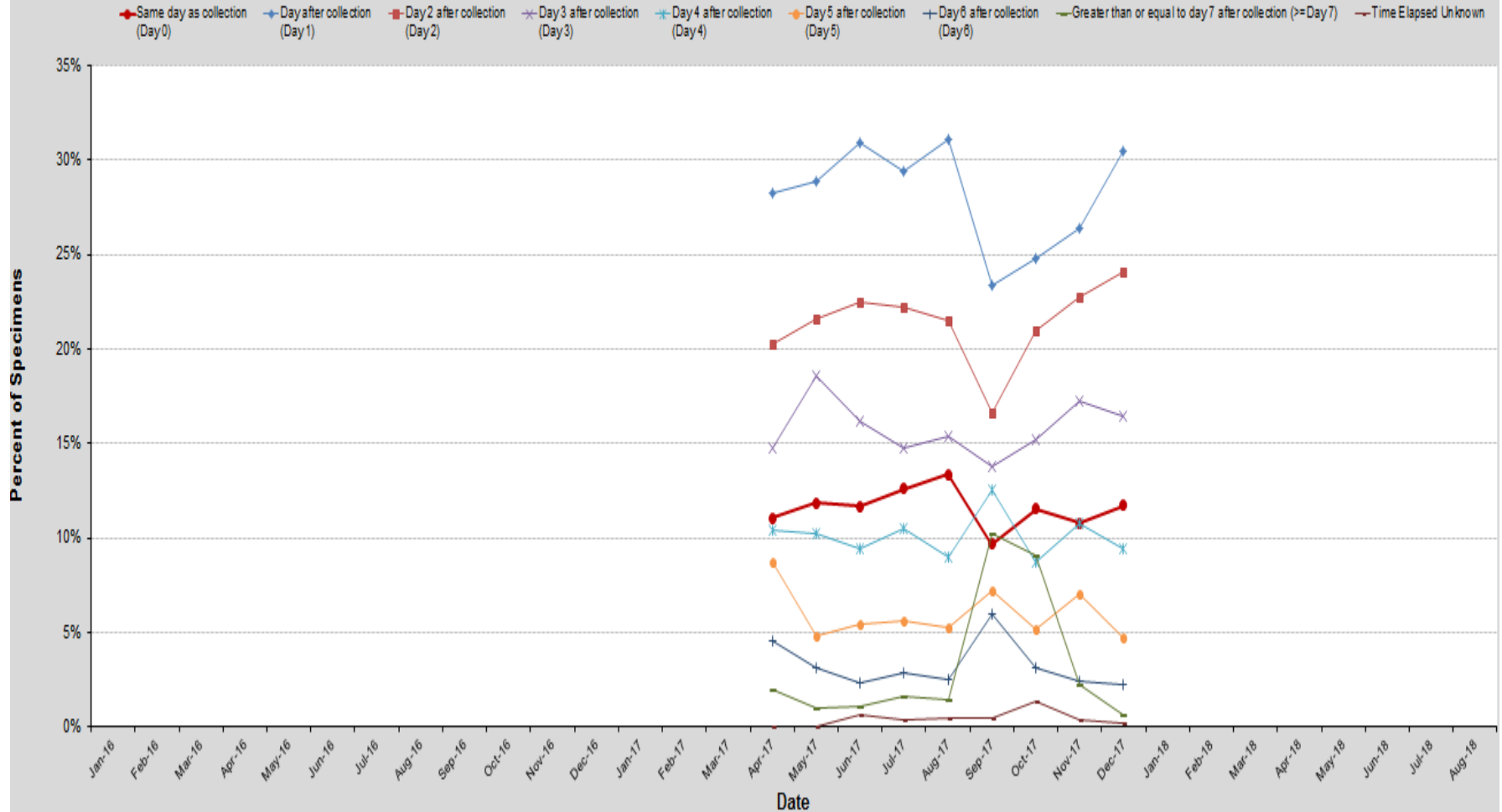
## 2. Sample collection



# Impact on PR NBS Service

## 2. Sample delivery to NBS laboratory

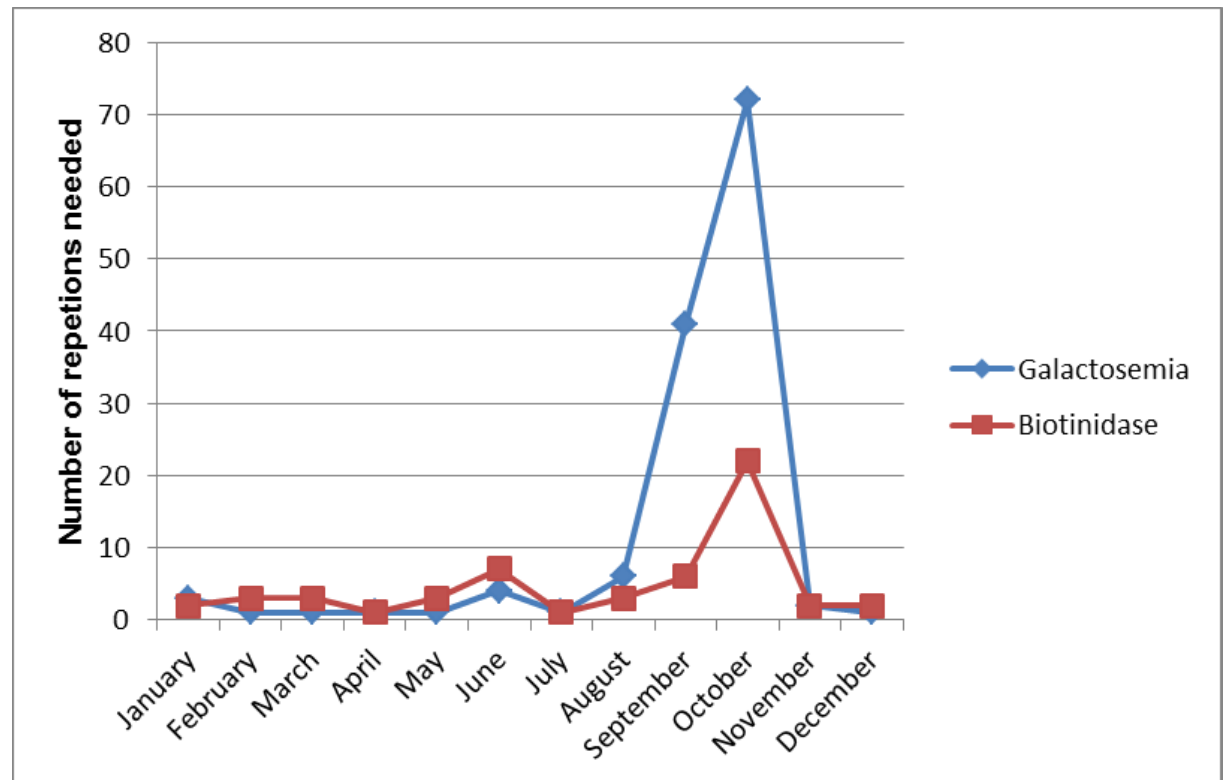
Quality Indicator 5b.i: Time from First Specimen Collection to Receipt by Lab



# Impact on PR NBS Service

## 3. Sample analysis and report of results

- Reduced personnel
- Appropriate inventory of reagents to cover for some weeks
- Increase in the number of repetitions for some tests
  - Aged samples
  - Not adequate storage of samples
- Manual report



# Impact on PR NBS Service

## 4. Follow up

### Situation:

- NO communication in our country
- Increase in the number of repetitions needed for some tests
- We were running with a delay
- 24 presumptive positive cases were identified the next weeks after Maria

### Strategies to find families:

- Social media (facebook, etc.)
- Police
- List of cases sent to hospitals
- Volunteers from different municipalities
- Mail office
- Text messages sent by our Follow-up staff during the day and night
- Our Follow-up supervisor visited two families to inform the results and bring the newborn to evaluation

### 2017

- 36 Confirmed Cases  
**39% identified after Maria**
  - 5 Metabolic Diseases
  - 5 SCD
  - 3 CH
  - 1 BIOT Deficiency
- All cases were efficiently managed with no consequences on newborns.

# Impact on PR NBS Service

## 4. Follow up

### Galactosemia and Biotinidase deficiency

**September and October:**

**Total of repetitions needed: 141**

**117 Repeated (83%)**

**8 Families left PR (6%)**

**16 Lost to follow-up (11%)**



# Back-up Plans for NBS Service

## ❖ Perkin Elmer

- NBS service included in one of our current contracts

## ❖ NY NBS Program

- Immediate assistance proposed by NY NBS Program with no contract in place
- Authorization was requested to the PR Department of Health to send samples to NY if necessary
- A draft contract was generated and is under revision

# Support from NBS Community

- **APHL**
- **CDC**
- **NY NBS Program**
- **NewSTEPS**
- **Other NBS Programs**



# 4 months after Maria.....

- 45% of residents are still without power
- Still with communication problems specially in rural zones
- Many people lost everything and they are now re-constructing
- Economical crisis
- We continue with a dramatic decrease in the number of births
- A long road to recovery!!!



# Lessons learned!!!

- Every NBS Program need to have a back up plan to provide the service during an emergency. Ideally, a contract with other laboratory should be in place prior the situation.
- Prepare for the worst, prepare for what you don't expect.
  - Evaluation of facilities
  - No water
  - No power; Is any backup power system available in your facility?
  - No internet
  - No communication with hospitals, families or healthcare providers
  - Reduced personnel
  - Birthing facility is not operational
  - Problems with the delivery of samples
  - No reporting system
- Do back-up constantly
  - Important files
  - List of pending cases
  - **You can lose everything in an emergency**
- Identify the state agencies or community groups to contact who can provide help with the NBS service during the emergency
- Revise emergency plans and develop strategies considering different situations
  - Discuss this plan with the staff and define roles

# Commitment and Resilience!!



# Thanks!!!

